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Association of Asthma Symptom Perception, Absenteeism, and Healthcare Utilization among children and their primary caregivers

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Chapter I: Statement of the Problem

Introduction

Asthma, although not a curable disease, is a disease that can be managed and controlled throughout one's life. Optimal asthma management and symptom control requires proper education about the disease, routine visits with a healthcare provider (HCP), adherence to a medication regimen and adequate support from family and the healthcare system. Parents' under-perception of children's asthma symptoms, discordance of their asthma illness beliefs with the professional medical model of asthma management, and inadequate medication adherence, may result in school absences, missed work for the parent and overutilization of emergency services and hospitalizations for the child.

Through daily use of an inhaled corticosteroid and adherence to a medical treatment plan, persistent pediatric asthma can be controlled and airway inflammation can be prevented (Drotar & Bonner, 2009). As recommended by the national guidelines, evidence shows that children who suffer from persistent asthma can have a reduction in symptoms with daily use of these preventative medications (Conn, Halterman, Lynch, & Cabana, 2007). However, "one factor that has been consistently implicated in the high rates of pediatric asthma-related morbidity is non-adherence to recommended medical treatment"(Drotar & Bonner, 2009) Compared with non-minority children, minority children use controller medication less often, have less continuity of care, and visit emergency departments more frequently(G. Canino et al., 2006; Essien, Mobley, Griffith, Creer, & Geller, 2001; Lara, Akinbami, Flores, & Morgenstern, 2006). Under-perception of asthma symptoms is a risk factor for ED visits, hospitalizations, and near-fatal/fatal asthma attacks in children (Magadle, Berar-Yanay, & Weiner, 2002). Children with severe bronchial hyper-responsiveness are at risk for missing the early stage of bronchoconstriction during asthma exacerbations (Motomura et al., 2009). A window of opportunity exists when asthma

patients can use bronchodilator medications in the days leading up to a severe asthma exacerbation to prevent its onset (Bjermer & Diamant, 2009; Tattersfield, Postma, Barnes, & et al., 1999). However, there has been very limited research on how to improve asthma symptom perception.

Background of the Problem:

The prevalence of asthma in the United States has grown by more than 15% since the last decade, and currently 7 million children in the United States suffer from asthma (CDC National Asthma Control Program, 2013). Especially noteworthy has been the increasing prevalence of asthma among the Latino population, primarily Puerto Rican children (L. J. Akinbami, LaFleur, & Schoendorf, 2002; L. J. Akinbami & Schoendorf, 2002). In general, 3,600,000 Hispanics reported in 2011 that they currently have asthma, with Puerto Rican Americans being affected by asthma two times more frequently than the overall American Hispanic population. Additionally, Puerto Rican children are 3.2 times more likely to have asthma than other Hispanic children, and Hispanic children overall are 40 percent more likely to die from asthma than non-Hispanic White children (U.S. Department of Health & Human Services , The Office of Minority Health, 2013).

Additionally, this disease costs the U.S. healthcare system $56 billion dollars annually or approximately $1,039 per child (CDC National Asthma Control Program, 2013). This estimate does not account for lost productivity costs due to children missing school and parents missing work. According to the most recent data from the Center for Disease Control, in 2008 asthma accounted for 10.5 million missed days of school and 14.2 million missed days of work. It can be assumed that with the rise of asthma morbidity that this number has also increased.

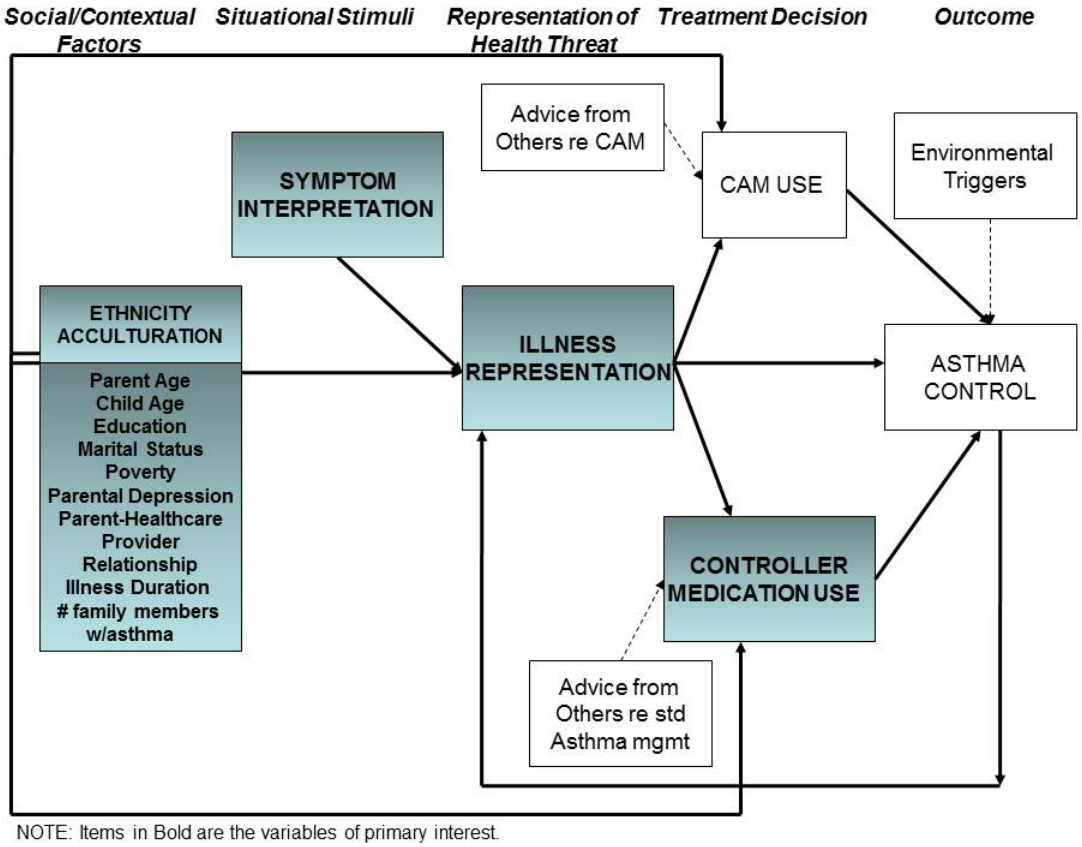
Purpose of Study: This secondary analysis examines the congruency between parental and child perceptions of asthma control with clinician rated control, the role of parent's

symptom perception and illness representations (IR) on controller medication use, and school absenteeism and healthcare utilization among a sample of Mexican and Puerto Rican parents and their children with asthma.

Significance of Study: The effects of asthma on children and their families is substantial, especially when it interferes with the child's ability to attend school, obtain adequate sleep and fully participate in activities of daily living (Hester et al., 2013). This is especially concerning given the high rates of asthma morbidity in the Latino population, specifically Puerto Rican Americans. This secondary analysis of data obtained from a larger study examining a multi-level explanatory model for health disparities among Latino children is important because it will assess and analyze how parent's perception of asthma control relates to clinician rated control, and how parent's illness representations of asthma, and absenteeism from school and work predict acute healthcare utilization. This information can then be used to address specific areas of concern in the Puerto Rican family's viewpoint/knowledge of the biomedical model of asthma control and can be used to reshape illness representations held by this population. Additionally, analysis of specific components of these data can be used to address gaps in the literature and expand the framework for assessing disparities in asthma health outcomes among Latino children, with a goal of creating a subsequent decrease in the number of emergency room visits, hospitalizations and missed school days.

Theoretical Framework: The Common Sense Model (CSM) of Illness Representations provides the theoretical framework for investigating the specified outcomes through the pathways of symptom perception, illness representations, and adherence to controller medications. Situational stimuli (perception of the child's symptoms), objective representation of the health threat (illness representation) with its treatment decisions (controller medication use) and appraisal of the outcomes (asthma control, pulmonary

function, healthcare utilization) are all described in this model and are all shaped by the parent's socioeconomic status, parent-healthcare provider relationship, and social and cultural beliefs held by the parent and family. The model contains a feedback loop with illness representations potentially changing over time as the parent gains experience in managing their child's asthma. Illness representations, treatment decisions, and appraisal of outcomes are influenced by the parent's sociodemographic characteristics (e.g., education, poverty, depression), social and cultural environment, and previous experiences managing their child's asthma. Figure 1 below illustrates the conceptual model for this study.



Research Questions: Aim #1: Examine parent and child perception of control compared to clinician rated control. Research Question (RQ) #1: Does parent and child perception of asthma control agree with clinician rated control? Aim #2: Examine parent's perception of their child's symptoms and their asthma illness representations as they influence adherence

to the child's medication regimen. RQ#2 Do parents who perceive their child's asthma to be well controlled, and whose illness representations align with the professional model for asthma management, have children with greater medication adherence? Aim #3: Examine how controller medication adherence relates to school absenteeism and acute healthcare utilization. RQ #3: How does adherence to the medication regimen, which is a function of parents' perception of their child's symptoms and their asthma illness beliefs, predict school absenteeism and acute healthcare visits?

Chapter II: Review of Literature

Symptom Perception

Family factors, such as how the family manages everyday symptoms and creates and identifies ways to avoid specific triggers of asthma symptoms, are important to the overall well-being of the child with asthma (Fiese & Wamboldt, 2003). Symptom perception is an area of important clinical investigation, as early and accurate recognition of symptoms by both the child and the parent, can be viewed as the "first step in a chain of events that lead to either effective or maladaptive asthma management" (McQuaid et al., 2007) Perception of asthma symptoms may directly contribute to patterns of medication use and asthma control. Asthma patients rely more on their subjective estimate of lung function than objective measures, such as peak expiratory flow, to guide use of asthma medications (controller and rescue)(Apter et al., 1997). If an individual overestimates the severity of his/her symptoms, there is a risk of over-utilization of the controller medications, while underestimation of symptom severity may lead to the failure to initiate or step-up therapy.

Puerto Rican children may be at risk for overperception of asthma symptoms. The Rhode Island/Puerto Rico Asthma Center (RIPRAC) study was the first multi-site study to examine ethnic differences in asthma symptom perception in children(Fritz et al., 2010). White children were the most accurate group (71%), followed by Latinos (62%; Puerto

Rican and Dominican children in RI), and island Puerto Rican children (55%). Errors made by Latino children were in the direction of over-perception of asthma symptoms. In a subsequent study by Feldman et al. (Feldman et al., 2012) significant ethnic differences on asthma symptom perception between Puerto Rican, African-American, and Afro-Caribbean children were not found; all children were accurate only 48% of the time without PEF feedback. Ethnic differences in the words used to describe asthma may contribute to under-perception of symptoms. African-American adults may use upper respiratory tract symptoms (e.g., tight throat) to describe asthma for themselves(Hardie, Janson, Gold, Carrieri-Kohlman, & Boushey, 2000; Hardie, Brown, & Gold, 2012) and their children(H. L. Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005). If families pay less attention to *lower* airway symptoms, this may lead to under-perception of *asthma* symptoms.

Asthma Illness Representations

The professional model for asthma management follows a stepwise approach in order to obtain the highest degree of asthma control, in which the dose, type of medications, and frequency of medication administration are adjusted based on the level of symptoms present(U.S. Department of Health & Human Services: National Asthma Education Program, 2007). According to the professional model, asthma is a chronic illness and is present regardless of the display of outward symptoms in the patient, thus daily adherence to the prescribed asthma medication regimen is viewed as instrumental in controlling this disease process (H. L. Yoos et al., 2007). In contrast, data obtained using the *Asthma Illness Representation Scale (AIRS©)* created by Dr. Arcoleo and colleagues (K. Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2010; H. L. Yoos et al., 2007), shows that parents "typically describe asthma as episodic, acute, and not readily controllable." Despite the fact that the highest score obtained from an analysis on parental illness representation by Yoos et al. indicated that the closest match to the professional model was in the subscale related to

facts about asthma (parents having fairly accurate knowledge about the pathophysiology, triggers and pharmacological aspects of this disease), the majority of children were on a suboptimal medication regimen and had poorly controlled asthma(K. Sidora-Arcoleo et al., 2010; H. L. Yoos et al., 2007). A qualitative study of young people with asthma and their caregivers was conducted by Callery, Milnes, Verduyn and Couriel,(Callery, Milnes, Verduyn, & Couriel, 2003) to examine these beliefs about asthma management in an effort to better understand the notion of "intelligent noncompliance." These researchers found that parents used the presence or absence of acute attacks as an indicator of asthma control and did not view asthma as a chronic illness. Parents reported that trial and error played a large role in the management of their children's asthma. The children reported modifying their medication regimens based on the presence or absence of symptoms. The researchers found that most parents and children viewed an acceptable level of symptoms and activity restriction as tolerable and normal for someone with asthma, even though effective medications were available that could render their children symptom-free.

The *AIRS*© instrument was created to further characterize the parents' asthma illness representations compared to the professional model of asthma management and this instrument can be used as a predictor of treatment adherence and asthma control. Previous research revealed that higher scores on the *AIRS*© instrument were indicative of beliefs that were congruent with the professional model of asthma management, fewer acute healthcare visits and more favorable relationships with the healthcare provider (HCP)(K. Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2012; H. L. Yoos et al., 2007). In a study utilizing the *AIRS*© instrument examining factors that influence parental asthma IR, including the parent/HCP relationship, it was found that the more education a caregiver reported, the closer their IR was to the professional model of asthma management(Peterson-Sweeney et al., 2007). However, despite asthma education received,

Callery et al.(Callery et al., 2003) found that healthcare professionals, the child suffering from asthma and their parents, all had different "perceptions of asthma control and management." The impact of formal education in relation to asthma outcomes might be more heavily influenced by the existing parental illness representation, which includes; prior illness history, generic information about health and illness, information from the HCP, information from family and friends, or from the internet(Leventhal, Leventhal, & Cameron, 2001; Peterson-Sweeney et al., 2007).

According to the illness representation theory, individuals construct their own common-sense model of disease and management in order to deal with illness and/or prevent the illness or disease (Leventhal et al., 2001). In relation to Latino families, there are several barriers that prevent adequate asthma management, such as access to healthcare, socioeconomic status, language barriers and slow acculturation to American health beliefs and practices. According to the data collected from the validation of the *AIRS*© instrument, poor parents' total score was significantly lower than non-poor parents which indicated a lay model asthma management viewpoint. Additionally, non-poor parents were shown to have more positive relationships with their HCP and more appropriate beliefs about contacting the HCP with questions/concerns than poor parents. Further, these results revealed that non-minority parents had higher total scores compared to minority parents reflective of beliefs aligned with the professional model. Minority parents held lay model beliefs and had a less positive relationship with their primary HCP (K. Sidora-Arcoleo et al., 2010).

Through the evidence presented from the pediatric asthma literature, positive relationships with the healthcare providers, where the health care provider allocates time to provide and reinforce asthma education, establishes realistic goals and clarifies and

identifies areas of misunderstanding/miscommunication, result in improved asthma health outcomes for the child (Peterson-Sweeney et al., 2007).

Role of Parental Symptom Perception and Asthma Illness Representations on Medication Adherence

Previous studies have suggested that a relationship between parental beliefs about their child's asthma medication and medication adherence exist and consist of both positive and negative feelings towards the effects and aftereffects of the controller and rescue medications utilized (Conn et al., 2007). In a cross-sectional survey of parents of children with asthma conducted by Conn et al., they found that only 14% of parents reported being fully adherent with their child's preventative asthma medication, and approximately one third of the parents had strong concerns about their child's medications, resulting in 17% of the parents reporting that concerns about the medication effects outweighed the necessity of using them (Conn et al., 2007). Minority parents were found to be more closely associated with the group who perceived medication usage concerns outweighing necessity of daily use. This is important because the results demonstrated that as the parents' beliefs about the necessity for medication increased relative to concern, an increase in adherence to the medication regimen was observed (Conn et al., 2007). Evidence from Yoos et al. (H. L. Yoos et al., 2007) supports this relationship between necessity and medication adherence stating that "parents whose illness representation was more concordant with the professional model of asthma had children who were more likely to be on an adequate medication regimen" (p.172).

Further evidence presented in a systematic review conducted by Drotar & Bonner, demonstrated that race (e.g., minority status) was a consistent demographic characteristic related to treatment nonadherence (8 out of the 9 studies) and socioeconomic status, including parental education and income, was associated with nonadherence in 7 out of 9

studies (Drotar & Bonner, 2009). Parental factors that are associated with adherence, as evidenced in Drotar & Bonner's review (6 of 7 studies), involved parental beliefs about asthma and medication treatment and its potential consequences. Specific beliefs associated with nonadherence included "medication side effects and lack of efficacy, low expectations for asthma control, or high perceived burden of treatment" (Drotar & Bonner, 2009). What demonstrated the most relevance to adherence to inhaled corticosteroid (ICS) treatment was parental "beliefs about asthma and medication treatment, with parents who perceived ICS medications as effective and necessary being more likely to adhere to recommended treatment regimens." What was identified as barriers to medication adherence were "beliefs that asthma medication was ineffective, had unwelcome side effects, was burdensome, or not necessary to sustain children's health" (Drotar & Bonner, 2009).

Additionally Yoos et al., found that demographic risk had a direct effect on medication regimen, with those at greatest risk having a less adequate regimen and informal-advice seeking being associated with a less adequate medication regimen (H. L. Yoos et al., 2007). Mansour, Lanphear and DeWitt (2000) found that many of the urban minority parents they interviewed in focus groups modified the asthma management plan prescribed by their child's healthcare provider based on personal health beliefs about the disease process and long-term consequences of the medication the child was receiving(Mansour, Lanpear, & DeWitt, 2000).

The identified risk factors for inadequate medication regimen are minority status, child age <=5 years, Medicaid insurance, children from Spanish-speaking families, concerns about side-effects and daily use of medication, and a misunderstanding about when controller medications should be used (Bauman et al., 2002; Bender et al., 2000; Farber et al., 2003; J. S. Halterman, Yoos, Sidora, Kitzman, & McMullen, 2001; Mansour et al., 2000; H. L. Yoos et al., 2007). What is important to note from the evidence presented, is that parental beliefs

demonstrated more powerful relationships with treatment adherence than their factual knowledge of asthma and prescribed medical treatment. This correlates to the previous section on parent and clinician perception of asthma control, as evidence shows that parents and healthcare providers are congruent in knowledge on asthma, but are more discordant in terms of the treatment plan and asthma medication regimen. Further, because asthma is episodic in nature, the child's ability to correctly identify asthma symptoms and the family's ability to enact an appropriate symptom management plan is critical in the optimal management of this disease and dependent on the adherence to the medication regimen prescribed (McQuaid et al., 2007). Studies have shown that asthma-related knowledge is not sufficient to enhance treatment adherence and needs to include motivation and the ability to apply knowledge to influence adherence (L. J. Akinbami, 2006; Gergen & Apter, 2007).

Parental Symptom Perception and Asthma Illness Representations on School Absenteeism and Acute Healthcare Utilization

In addition to the10.5 million missed days of school and 14.2 million missed days of work reported by the CDC in 2008, additional data collected by Hasegawa, Tsugawa, Brown, & Camargo on childhood asthma hospitalizations in the U.S. from 2000-2009, reported that asthma accounted for approximately 7.5 million outpatient visits, 640,000 emergency department visits and 157,000 hospitalizations (Hasegawa, Tsugawa, Brown, & Camargo Jr, 2013). Asthma hospitalizations represent a serious adverse outcome because asthma and its disease process can, in theory, be well controlled and maintained with "high-quality healthcare, patient education and optimal management of asthma" (Hasegawa et al., 2013).

As reported by Hester et al.(Hester et al., 2013), children had a higher average emergency department visit rate compared with adults (10.7 versus 7.0 per 100 persons with asthma), which suggest that almost 3 children in any given classroom of 30 have

asthma (Moorman, J.E., Akinbami, L.J., Bailey, C.M., et al., 2012). Additionally, results by Hasegawa et al. indicated that asthma accounted for 2.3% of all hospitalizations in US among children <18 years of age and in more recent years, the hospitalized children were more likely to be Hispanic compared to white children and be insured by Medicaid or Medicare (Hasegawa et al., 2013) .

Data collected from a study on parental knowledge of preventative asthma care occurring in the pediatric emergency department of two urban tertiary care centers, one in the southwest and one in northwest of the United States, found that almost two thirds (66%) of the children sampled had visited the ED for an asthma exacerbation within the 12-month period preceding the current visit. Additionally over half of the children (55%) had previously been hospitalized for more than a 24-hour timeframe for asthma (Deis, Spiro, Jenkins, Buckles, & Arnold, 2010). Further, 93% of the children had a PCP but only 62% of these children had attended a preventive asthma care visit during the 12-month period preceding the current ED visit. Other data analyzed included preventative asthma care and self-management, parental knowledge of preventative care and parental perception of their ability to provide asthma care. What was most significant in the findings was that the results suggested that parents of children with asthma presenting to the urban tertiary pediatric emergency departments with asthma exacerbations, frequently had insufficient knowledge of the preventative care measures needed to keep their child well, and many of the children lacked the required self-management tools such as peak flow meters and asthma action plans(Deis et al., 2010). The findings of this research highlights the need for improved asthma education at multiple levels of care such as in schools, primary care clinics, urgent care centers and the emergency department to keep these children from missing school, parents missing work and the utilization of acute healthcare services.

Areas of most importance in terms of asthma education should revolve around the appropriate use of a daily inhaled corticosteroids regimen, the creation of an individualized asthma action plan, avoidance of environmental triggers such as second hand smoke and the administration of a yearly flu vaccine (Deis et al., 2010).

Evidence from a school based asthma therapy intervention, trialed in Rochester, New York, demonstrated that through initiating administration of the controller asthma medication at school by the school nurse, children in the treatment group experienced nearly one additional symptom free day over 2 weeks compared to the usual care group and these children experienced fewer nights with symptoms, fewer days requiring rescue medication and missed fewer days of school due to asthma (J. Halterman et al., 2012). Further, evidence from another review on state enforced school based asthma interventions showed that through the initiation of standardized state asthma programs, school based asthma programs would have the ability to connect and collaborate with "state and regional stakeholders with different backgrounds in medical management, environmental health, and health education"(Hester et al., 2013). This would allow a more unified acceptance and implementation of such programs within the schools, which in turn would multiply the success rate seen in such asthma interventions. What can be shown by the study from Halterman et al. is that evidence supports interventions targeted at care in community settings which are particularly effective for vulnerable populations, as the studied sample in this intervention comprised of children who were 57% African American and 26% Hispanic, with the majority (70%) being covered by Medicaid insurance (J. Halterman et al., 2012).

Chapter III: Methodology

Research Design: This is a secondary data analysis, using the baseline data, from a longitudinal study of parental illness representations and controller medication use among a diverse sample of 267 Latino families (primarily Mexican and Puerto Rican) of children

with asthma aged 5-12. Structured interviews occurred with parents and shorter interviews with the children and objective measures of children's lung function, as well as a review of the children's medical records. Interviews and assessments were conducted at enrollment, and months 3, 6, 9, and 12 post-enrollment. Chi-square, t-tests, and linear regression analyses were conducted.

Population and Sample Design: Baseline data were collected from 514 Mexican and Puerto Rican caregivers and their children, ages 5-12, who had asthma requiring the daily use of controller medications. This population was chosen based on the presumption that children in this age range have not typically assumed daily control for managing their own asthma; they are still heavily dependent on their caregivers. Families were recruited from clinics in Phoenix, Arizona and Bronx, New York where there are higher populations of inner-city poor Mexican and Puerto Rican children with asthma. It was necessary to enroll multiples sites in this study, in order to obtain a sufficient number of families to participate and conduct the study. A description of each site is presented below.

The Neighborhood Action Outreach for Health (NOAH) program, administered by the Scottsdale Healthcare organization (SHC), provides primary care services, preventive healthcare, and immunizations for uninsured and under-insured children and families through a mobile unit and two school-based health clinics. Approximately 3,248 children receive urgent primary care services, 647 children receive routine, preventive primary care services, and 1,383 dental visits are provided through the NOAH health centers annually. The NOAH nurse practitioners and medical staff provide much-needed health education to parents through counseling, exhibits, and health screenings for diabetes, asthma, blood pressure, vision, and hearing. Well-child checks and sports physicals are performed at NOAH sites as well. These clinics serve primarily poor Mexican families with no health insurance. Approximately 22% of the children served have a diagnosis of asthma. Dr.

Sidora-Arcoleo purchased and installed spirometry equipment in each of the clinics and trained the staff in its use. These clinics now incorporate asthma screening procedures per the NAEPP's Expert Panel Report clinical guidelines (U.S. Department of Health & Human Services: National Asthma Education Program, 2007) and it is anticipated that this asthma prevalence rate will increase due to enhanced detection.

The Phoenix Children's Hospital (PCH) Breathmobile is a self-contained mobile asthma clinic that travels to inner-city schools providing asthma identification, teaching, treatment, and follow-up. Since the inception of the Breathmobile, there has been a greater than 40% reduction in missed school days and a greater than 70% percent reduction in emergency room visits due to asthma-related problems, and a greater than 73% decrease in asthma-related hospital stays among Breathmobile patients. The Breathmobile visits 19 schools in South Phoenix, where children are more likely to be uninsured. The service requires no referral and there is no charge for treatment. Once diagnosed, the children receive an asthma action plan that includes education for asthma self-management, follow-up appointments and evaluations, controller medications, and a 24-hour phone number in case questions arise. The Breathmobile staff sees 70 school-aged patients a week and includes a pediatric nurse practitioner, a registered nurse, a respiratory therapist, and an operations coordinator. Seventy-seven percent of the population served is Latino (primarily Mexican), 13% black, and 5% white.

The pediatric clinic at Jacobi Medical Center (JMC) serves an ethnically diverse group of children who have a broad range of asthma severity. At JMC, there are approximately 2,634 visits to the Pediatric Asthma Clinic, 2,507 visits to the Pediatric Allergy Clinic, 40,535 visits to the General Pediatrics Clinic, and 3,182 asthma-related ER visits per year. The racial/ethnic breakdown of asthma visits at JMC is 51% Latino (of those 48% are Puerto Rican) and 30% Black/African-American.

Data Collection Procedures: To be eligible for the study, children must have met the following criteria: a) The child had to be between the ages of 5 and 12, b) had a diagnosis of asthma as obtained from their medical record, c) identified as Latino as described by the child's primary care caregiver, d) had no other significant pulmonary complications or conditions, e) participating parent must have had the majority responsibility for the child's day-to-day asthma management and care, f) no cognitive learning disability that would interfere with the parent or child's ability to participate in the interview process. Computerized data systems within each recruitment site were used to identify patients who fit the specified diagnosis, age, and ethnicity. Eligible families were recruited through face-to-face invitations during clinic visits, by mailing recruitment letters from the health care provider to potential families, and by making phone calls inviting families to participate. The research nurse/assistant (RNA) at each practice site explained the study and reviewed eligibility criteria with each family before obtaining verbal assent to participate. An appointment was then made for the parent and child to complete the informed consent, child verbal assent, interviews, and spirometry tests. All materials were made available in both English and Spanish.

The RNA conducted a structured interview with the parent that included the AIRS, Parent/Health Care Provider Relationship Scale(K. Sidora-Arcoleo et al., 2010; K. J. Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2010), Parent-Childhood Asthma Symptom Checklist, Asthma Trigger Inventory (Ritz, Steptoe, Bobb, Harris, & Edwards, 2006) and Stephenson Multigroup Acculturation Scale (Stephenson, 2000) as well as information regarding demographics, the child's asthma control, controller medications, and any alternative therapies that are currently being used. Interviewers conducted the interview in either English or Spanish based on the parent's preference, and each took approximately 60

to 90 minutes. Interviews were completed at enrollment and 3, 6, 9, and 12 months post-enrollment.

Child interviews and spirometry maneuvers were done independently of the parent interviews. Spirometry was done per the guidelines set forth by the American Thoracic Society, and the child continued to use his/her prescribed medications prior to any tests. The interview with the child included the Asthma Control Test and the Childhood Asthma Symptom Checklists in order to assess the child's reports of symptoms during asthma exacerbations. Interviews were conducted in Spanish or English based on the child's preference and took approximately 20 to 30 minutes. The spirometry assessment took place after the interview. Children completed interviews and assessments on the same schedule as the parents.

Data Collection Instrument

Ethnicity: Parents were asked to indicate their country of birth. They were also asked to specify which ethnic group they most closely identified with (Mexican, Puerto Rican, Cuban, Dominican, Central American, South American, or other).

Demographic Measures: Perception of poverty is a stronger predictor than actual income of certain psychiatric disorders (G. Canino et al., 2004) and ataques de nervios (Guarnaccia, Martinez, Ramirez, & Canino, 2005) among Puerto Rican children and has been associated with functional morbidity among African-American and Puerto Rican children, but not Anglo children (Koinis-Mitchell et al., 2006). Using a measure adapted by Gore et al. (Gore, Aseltine, & Colton, 1992), parents were asked "What best describes your family's standard of living?" Response choices ranged from very well off to poor. From the Parent Interview, we obtained the parent's age, educational level, marital status, and employment status. Perception of poverty, educational level, marital status, and employment status are being measured at all follow-up assessments as these variables may change over time. From the

child's medical record, we obtained the child's age, gender, date of asthma diagnosis (if known), and type of health insurance.

Illness Representation: The construct of IR is comprised of the five subscales of the AIRS© and the total score. The five subscales contain items which assess beliefs about the facts about asthma, the nature of asthma symptoms, treatment expectations, attitudes towards medication use, and the emotional aspects surrounding medication use. This instrument is designed to identify barriers and risk factors for under-utilization of controller medications that can be used in research and healthcare settings. The English version of the AIRS© tool was developed and validated among an ethnically diverse sample; primarily white, black, and Puerto Rican (K. Sidora-Arcoleo et al., 2010; H. L. Yoos et al., 2007; H. L. Yoos, Kitzman, & McMullen, 2003). There are five subscales for the AIRS© tool, in addition to an overall score. These subscales are: (1) treatment expectations (8 items, α=0.75); (2) attitudes towards medication use (8 items, α=0.78); (3) facts regarding asthma (11 items, α=0.71); (4) the nature of asthma symptoms (5 items, α=0.61); and (5) emotional aspects of medication use (5 items, α=0.55). The Cronbach's alpha for the overall scale score was 0.84(K. Sidora-Arcoleo et al., 2010; H. L. Yoos et al., 2007). Each item is scored on a 5-point Likert scale with 1 (strongly agree) to 5 (strongly disagree). When necessary, items within each subscale are reverse scored so that higher values indicate closer alignment with the professional model for asthma management. The subscale and total score are calculated as the mean of the non-missing items. The scale has been translated to Spanish following accepted translation/back-translation methodology and was validated among a sample of Mexican and Puerto Rican families by Drs. Sidora-Arcoleo & Feldman(K. J. Sidora-Arcoleo et al., 2010).

Objective Assessment of Asthma Control: Asthma symptom control will be assessed through the parent and child interviews and child spirometry assessment per the National Asthma

Education and Prevention Program's Expert Panel Reports clinical guidelines (U.S. Department of Health & Human Services: National Asthma Education Program, 2007). The guidelines state that an assessment of severity is conducted for children not currently on long term control medications and that once therapy is initiated, an assessment of control is completed. There are four severity groups (intermittent, mild persistent, moderate persistent, and severe persistent) and three control groups (well-controlled, not well controlled, and very poorly controlled). Dr. Radford (Phoenix) and Dr. Serebrisky (Bronx), pediatric pulmonologists, assign the child's severity or control level, as appropriate, based on the parent's and children's responses to structured questions regarding daytime symptoms, nocturnal symptoms, activity limitations, use of short-acting β2 agonists for the 2-4 week period prior to the interview, and lung function tests conducted during the child's portion of the interview per the 2007 NAEPP Expert Panel Report Guidelines.

Subjective Report of Asthma Control: The children completed the Asthma Control Test (ACT) – a short (5-7 items depending on age), validated instrument for assessing asthma control. The original ACT was developed, tested, and validated for use in subjects age 12 years and older (Nathan et al., 2004). This 5-item instrument exhibits good reliability and validity as a short screening tool. The items consist of a subjective assessment of control and frequency estimates of how often asthma keeps the respondent from getting things done, how often the respondent had shortness of breath and nighttime awakenings, and how often the respondent had to use an inhaler or nebulizer. Cronbach's alpha=0.84 and the ACT demonstrated a significant correlation with specialists' assessment of control (r=0.45, p=0.0001). A cut point of 19 showed the highest area under the ROC curve (0.73) and overall agreement with the specialists' rating of control was 74.1% (Nathan et al., 2004). Scores < 19 are indicative of poorly controlled asthma. Recently, a version for children ages 4-11 years (C-ACT) was developed and validated (Liu et al., 2007). This is a 7-

item instrument with 4 items completed by the child (how is your asthma today, do you cough because of asthma, do you wake up at night because of your asthma, and is asthma a problem when you run, exercise, or play sports) and 3 items by the caregiver (frequency in the past 4 weeks of daytime symptoms, wheeze, and nighttime awakenings). Potential scores range from 0-27. Cronbach's alpha=0.79 and the C-ACT exhibited moderate to strong correlations with parent and child quality of life measures (r=0.47, r=0.68, respectively). Cut-point score analyses for the C-ACT yielded similar results to the ACT. A cut point of < 19 indicates poorly controlled asthma and correctly classifies children 72% of the time (Liu et al., 2007). Because the sample for this study will range in age from 5-12, we will administer the age-appropriate version. The ACT has undergone Spanish linguistic translation and validation and has been shown to be a reliable and valid Spanish-language instrument for assessing control. Cronbach's alpha was 0.84 and the intra-class correlation coefficient was 0.85. Higher ACT scores were negatively related to exacerbations and positively related to lower symptom intensity and frequency. Sensitivity and specificity were 71.3% and 85.4%, respectively. Consistent with the original version, a score > 19 classifies asthma symptoms as "well-controlled." Scores of 12-19 indicate "not well-controlled" asthma symptoms and scores <12, "very poorly controlled" asthma symptoms (Vega et al., 2007). A validated Spanish version of the C-ACT is not available. We translated/back-translated this instrument per accepted methodology.

Data Analysis

Eligible participants who decline to participate were compared with those enrolled on demographic characteristics to check for sample bias. Descriptive statistics identified the distribution of data and total instrument scale scores for each of the study surveys. Means and standard deviations were examined for continuous variables and proportions for categorical variables. Chi-square, t-tests, and linear regression analyses were conducted.

Non-normal Distributions: Full attention was given to the distributional properties of variables and to regression diagnostics. We made appropriate adjustments for outlying data points.

Chapter IV: Research Results:

Table 1. Enrollment Table

Site	A. Total Enrolled	B. # of Dropouts	C. Adjusted Total of Enrolled (A-B=C)	D. # of Dropouts that completed 3+ interviews	E. # of "past due" families that have completed at least 3 interviews
PCH	105	7	98 (148, PCH+SHC)	0	1
SHC	53	3	50	1	2
Jacobi	114	38	76	8	9
Total	272	48	224	9	12

- PCH: Phoenix Children Hospital
- SHC: Scottsdale Healthcare organization who administers The Neighborhood Action Outreach for Health (NOAH) program
- Jacobi: Jacobi Medical Center

Table 2. Post-Enrollment Data Collection Table

Site	3-Month	6-Month	9-Month	12-Month (Completed)
PCH	92	86	87	81
SHC	43	37	44	45
Jacobi	57	49	48	49
Total	192	172	179	175

Table 1 presents the enrollment data and follow-up assessments completed as of 3/31/14. Data collection is ongoing and the baseline data were used in this project. The overall attrition rate to date is 17.6%. This is lower than the 20% estimated for the power calculations. When we examined attrition by site, we discovered that the rates were quite low at both Phoenix sites (5.7% at the school-based health clinics and 6.7% at the

Breathmobile). The higher than anticipated attrition rate in New York, 33.3% occurred due to four natural disasters which occurred in a 2 year period. There was hurricane Sandy, two blizzards, and a power failure. A number of our families were displaced from their homes when the hurricane hit and ended up moving out of the area.

Representativeness of Sample: The sample recruited from the Bronx was representative of the Bronx population as whole based on caregiver's age and education level and poverty status. The population in Phoenix, AZ is very diverse socioeconomically and thus, the sample recruited here was not representative of the population regarding education and poverty level. Our families, on average, had lower education levels and more were classified as living in poverty. The average adult age was comparable.

Profile of Sample/Population:

Sample Baseline Characteristics

Variable	**Mexican (*N*=188)**	**Puerto Rican (*N*=79)**	**Test of Significance**
	N (%)	*N* (%)	*p*-value
Employment Status			
None	114 (60.6)	61 (77.2)	**.01**
Part-time	42 (22.3)	6 (7.6)	
Full-time	32 (17.0)	12 (15.2)	
Married (% Yes)	104 (55.3)	24 (30.4)	**.0002**
Poor (% Yes)	126 (67.0)	25 (31.7)	**<.0001**
High School Graduate (% Yes)	85 (45.5)	48 (60.8)	**.02**
Caregiver Sex (% Female)	180 (95.7)	74 (93.7)	NS
Child Sex (% Female)	62 (33.0)	32 (40.5)	NS
Severity Accuracy-Child			
Under-perception	110 (59.5)	51 (68.0)	NS
Accurate	44 (23.8)	14 (18.7)	
Magnification	31 (16.7)	10 (13.3)	
Severity Accuracy-Parent			
Under-perception	103 (55.4)	46 (61.3)	NS
Accurate	47 (25.3)	15 (20.0)	
Magnification	36 (19.4)	36 (18.7)	
Ever Used CAM (% Yes)	133 (70.7)	65 (82.3)	**.05**
Currently Using CAM (% Yes)	102 (54.3)	56 (70.9)	**.01**
Use OTC Medications for Asthma (% Yes)	59 (31.4)	19 (24.1)	NS
Clinical Depression-Parent (%	45 (23.9)	34 (43.0)	**.002**

Yes)			
ACT Control-Child (% Inadequate)	82 (43.6)	67 (84.8)	**<.0001**
ACT Control-Parent (% Inadequate)	177 (94.2)	64 (81.0)	**.001**
Clinician Rated Control			
Well-controlled	102 (57.0)	25 (36.2)	**.01**
Not well-controlled	64 (35.8)	35 (50.7)	
Poorly controlled	13 (7.3)	9 (13.0)	
Clinician Rated Severity			
Mild Intermittent	32 (7.2)	11 (14.7)	**.01**
Mild Persistent	63 (33.9)	16 (21.3)	
Moderate Persistent	74 (39.8)	31 (41.3)	
Severe Persistent	17 (9.1)	17 (22.7)	
Controller Medication: Past year (% Yes)	140 (74.5)	67 (84.8)	NS
Controller Medication: Past month (% Yes)	130 (69.2)	62 (78.5)	NS
Controller Medication: Past 24 hours (% Yes)	108 (57.5)	50 (63.3)	NS
Any ED Visits: Past Year (% Yes)	58 (30.9)	57 (72.2)	**<.0001**
Any hospitalizations: Past Year (% Yes)	21 (11.2)	20 (25.3)	**.003**
Frequency of missed school			
None	61 (32.5)	17 (21.5)	
1-2 times/yr	54 (28.7)	16 (20.3)	**.03**
3-4 times/yr	34 (18.1)	15 (19.0)	
5-6 times/yr	11 (5.9)	8 (10.1)	
≥7 times/yr	28 (14.9)	23 (29.1)	
	Mean (SD)	**Mean (SD)**	**p-value**
# Family Members w/Asthma	1.24 (.73)	0.91 (1.09)	**.02**
Asthma Duration (Months)	67.94 (39.54)	88.46 (31.77)	**<.0001**
Caregiver's Age	35.47 (6.31)	38.42 (10.47)	**.02**
Study Child's Age (Years)	9.67 (2.15)	9.23 (2.23)	NS
# Years Caregiver Lived in US	14.05 (7.75)	33.88 (13.00)	**<.0001**
# Years Study Child Lived in US	8.39 (2.27)	8.23 (2.78)	NS
ACT Score: Parent	28.72 (5.62)	25.38 (6.56)	**<.0001**
ACT Score: Child	19.91 (3.82)	16.46 (3.92)	**<.0001**
Social Network Score	3.19 (.47)	2.95 (.54)	**.0004**
Social Network: Family	3.23 (.54)	2.89 (.70)	**.0001**
Social Network: Friends	3.14 (.55)	3.01 (.61)	NS
AIRS: Nature of Asthma Symptoms	2.74 (.66)	2.72 (.63)	NS
AIRS: Facts About Asthma	3.56 (.41)	3.58 (.34)	NS
AIRS: Attitudes re Medication Use	2.66 (.62)	2.73 (.56)	NS
AIRS: Treatment Expectations	3.07 (.59)	2.75 (.45)	**<.0001**
AIRS: Emotional Aspects re Medication Use	2.98 (.79)	2.86 (.71)	NS
AIRS: Total Score			

Parent-Provider Relationship	3.72 (.54)	3.78 (.55)	NS
Parental Depression (CES-D)	10.95 (10.15)	16.03 (12.03)	**.002**
Asthma Symptom Checklist (P-CASCL): General	5.98 (17.30)	58.42 (13.81)	NS
Asthma Symptom Checklist (P-CASCL): Panic-Fear	30.89 (11.88)	30.58 (12.24)	NS
Asthma Symptom Checklist (P-CASCL): Irritability/Hyperventilation	19.92 (8.10)	21.42 (8.00)	NS
# ED Visits: Past Year	0.30 (.65)	0.73 (.86)	**<.0001**
# Hospitalizations: Past Year	0.07 (.25)	0.25 (.54)	**.005**
Acculturation: Ethnic Society Immersion	3.23 (.35)	3.22 (.41)	NS
Acculturation: Dominant Society Immersion	2.98 (.39)	3.40 (.44)	**<.0001**
Asthma Trigger Inventory: Infection	1.82 (.95)	1.75 (1.00)	NS
Asthma Trigger Inventory: Irritants	1.14 (.99)	1.28 (.94)	NS
Asthma Trigger Inventory: Exercise	1.20 (.89)	1.05 (.80)	NS
Asthma Trigger Inventory: Psychological	0.48 (.63)	0.40 (.57)	NS
Asthma Trigger Inventory: Pollen	1.75 (1.22)	1.73 (1.16)	NS
Asthma Trigger Inventory: Animals	0.91 (1.04)	1.30 (1.10)	**.006**
Asthma Trigger Inventory: All Allergens	1.36 (1.01)	1.56 (1.00)	NS

Based on the statistical data provided above, there are some noteworthy differences in some of the variables between Mexican and Puerto Rican caregivers and their children affected by asthma. Compared to Mexican caregivers, Puerto Rican caregivers are older, more likely to have a high school degree but be unemployed, less likely to be married or poor, lived in the U.S longer, report higher numbers of depressive symptoms, and reported greater dominant society immersion. The social network scores of Puerto Rican caregivers were significantly lower than that found for Mexican caregivers.

Puerto Rican caregivers also reported higher numbers of animal asthma triggers and having a higher prevalence of asthma among family members. Additionally, there is a higher percentage of Puerto Ricans who have used complementary alternative medication (CAM) and a higher percentage that are currently using CAM than Mexicans. This can be

reflected in the finding that Puerto Rican's compared to Mexican's have an overall decreased AIRS© treatment expectation than Mexican's and scored lower on the ACT questionnaire for both the child and parent.

Puerto Rican children reported longer asthma direction, had a greater incidence of Emergency Room visits in the past year, as well as hospitalization, and Puerto Rican children missed school at a higher frequency rate than Mexican children. Additionally, clinician rated control for Puerto Rican children was more likely to be stated as not well controlled or poorly controlled, and there was a higher proportion of children classified as moderate or severe persistent by the clinician compared to Mexican children.

Reliability of Instrument

The AIRS© Cronbach's alphas were 0.55 Nature of Asthma, 0.64 Facts about Asthma, 0.73 Attitudes towards Medication Use, 0.57 Treatment Expectations, 0.67 Emotional Aspects of Medication Use, and 0.77 for the total score. The Parent Provider Relationship Cronbach's alpha = 0.74.

Summary of Findings

Aim #1 Parent-Clinician rated control

	Parent's Perception of Control			
		Not -Controlled	**Well-controlled**	**Total**
Clinician Control Rating	**Not Controlled**	41	80	121
	Row Percent	33.9%	66.1%	100%
	Column Percent	77.4%	41%	48.8%
	Well-Controlled	12	115	127

	Parent's Perception of Control			
	Row Percent	9.5%	90.6%	100%
	Column Percent	22.6%	59%	51.2%
	Total	53	195	248
	Row Percent	21.4%	78.6%	
	Column Percent	100%	100%	

$X^2 = 22.02$, $p < .05$

The chi-square test shows that there is a statistically significant difference between the perception of control of parents and the clinician control rating (above table). Most parents are in agreement with clinicians regarding level of asthma control (63%) but there is also a significant portion of parents that perceive their child as well-controlled when the clinician is saying that they are not well-controlled (32%).

Aim #2 Controller Medication Adherence:

Variable	Estimate (SE)	Wald X^2	p-Value
Ethnicity	0.23 (0.17)	1.91	.17
AIRS Score	-0.53 (0.45)	1.39	.24
Parental Perceptual Accuracy			
Under-perception vs. accurate	-0.81 (0.20)	16.46	**<.0001**
Magnification vs. accurate	0.22 (0.23)	0.96	0.33

*Modeling the probability of non-adherence

There were no statistically significant differences in adherence based on ethnicity, asthma illness representations, or between parents who were accurate versus those who under-perceived symptoms. Compared to parents who were accurate, parents who

magnified the severity of their child's symptoms were significantly more likely to be adherent.

Aim #3 ED Visits*:

Variable	Estimate (SE)	Wald X^2	p-Value
Ethnicity	0.86 (0.16)	30.90	**<.0001**
AIRS Score	1.21 (0.44)	7.64	**.006**
Parental Perceptual Accuracy			
Under-perception vs. accurate	0.18 (0.19)	0.87	.35
Magnification vs. accurate	-0.58 (0.24)	5.98	**.01**

*Modeling the probability of no ED visits

Compared to Puerto Rican children, Mexican children were significantly <u>less</u> likely to have had an ED visit in the past year. In addition, children of parents whose illness representations were aligned with the professional model were less likely to have made an ED visit. The difference in ED visits between parents who were accurate and those who under-perceived a symptom was not statistically significant. Compared to parents who were accurate, those who magnified (perceived symptoms to be more severe than they actually were) had significantly more ED visits.

Aim #3 Hospitalizations*:

Variable	Estimate (SE)	Wald X^2	p-Value
Ethnicity	0.43 (0.18)	5.58	**.02**
AIRS Score	0.69 (0.56)	1.53	.22
Parental Perceptual Accuracy			
Under-perception vs. accurate	-0.20 (0.25)	0.65	.42
Magnification vs. accurate	-0.41 (0.30)	1.85	.17

*Modeling the probability of no hospitalizations

Compared to Puerto Rican children, Mexican children were significantly <u>less</u> likely to have had a hospitalization in the past year. There were no statistically significant differences in hospitalizations based on illness representations or perceptual accuracy.

Aim #3 Missed School*:

Variable	Estimate (SE)	Wald X^2	p-Value
Ethnicity	0.30 (0.12)	5.76	**.02**
AIRS Score	0.26 (0.34)	0.60	.44
Parental Perceptual Accuracy			
Under-perception vs. accurate	-0.07 (0.15)	0.19	.66
Magnification vs. accurate	-0.13 (0.19)	0.46	.50

*Modeling the probability of missed school days

Compared to Mexican children, Puerto Rican children were significantly more likely to have missed any school in the past year. There were no statistically significant differences in missed school days based on illness representations or perceptual accuracy.

Chapter V: Conclusions and Recommendations

Conclusion:

Compared to other Latino populations, more specifically to the Mexican population studied in this analysis, Puerto Rican children have an increased rate of acute healthcare utilization and hospitalization and have a higher rate of clinician perceived severity and poorly controlled asthma. While most parents are in agreement with clinicians regarding the level of the child's asthma control as supported by the data, a significant portion of parents hold incongruent perceptions of control, with parents rating their child as well controlled, when the clinician states that the child is not, based on the constructs of the professional model for asthma management. Discrepancies in this viewpoint directly attribute to decreased compliance in medication adherence as stated in several studies present in the literature. What is important to note from the evidence found from this study, as well as the evidence from the literature presented in the first part of this document by McQuaid et al, is that parental beliefs demonstrate more powerful relationships with treatment adherence than their factual knowledge of asthma and prescribed medical treatment (McQuaid et al., 2007). This is important because when parental perception of control and clinician perception of control are discordant, decreased compliance in

medication use and adherence to the asthma action plan occurs.

Further, data from this study show that those caregivers who magnified symptoms, or perceived them as more severe than they actually were, were more likely to utilize emergency services. This relays back to evidence previously presented above, which states that education received by the parent from the healthcare provider may be more heavily influenced by the existing parental illness representation, which includes; prior illness history, generic information about health and illness, information from the HCP, information from family and friends, or from the internet (Leventhal et al., 2001; Peterson-Sweeney et al., 2007), and that these beliefs should be assessed when the healthcare provider creates the child's personalized asthma action plan.

This is of specific importance for the Puerto Rican population, as Puerto Rican children may be at risk for over-perception of asthma symptoms, as they have a higher prevalence of somatization (i.e., medically unexplained) symptoms than Mexican-Americans, independent of age, gender, and SES (I. A. Canino, Rubio-Stipec, Canino, & Escobar, 1992; Escobar, Rubio-Stipec, Canino, & Karno, 1989; Shrout et al., 1992). This over-peception is called "ataques de nervios," which is a reaction to a stressful event that includes multiple behavioral (e.g., screaming, crying) and physical symptoms, and feeling out of control (Guarnaccia, 1993) and may have an impact on illness expression in Puerto Rican culture. Puerto Rican children with asthma attacks are twice as likely to have a parent who has ataques and depression compared to children without asthma and this modeling of frequent physical symptoms by adults via somatization and ataques, may influence illness expression among Puerto Rican children and lead to over-perception of asthma symptoms.

This is of great importance as children with severe bronchial hyper-responsiveness are at risk for missing the early stage of bronchoconstriction during asthma exacerbations (Motomura et al., 2009). A window of opportunity exists when asthma patients can use

bronchodilator medications in the days leading up to a severe asthma exacerbation to prevent its onset (Bjermer & Diamant, 2009; Tattersfield et al., 1999). Through increased investigation of the healthcare provider about such beliefs about asthma and cultural factors such as "ataques de nervios," in the Puerto Rican population, a higher rate of clinician and parental agreement of control and a subsequent decrease in acute healthcare utilization and hospitalization may occur.

Limitations:

The greatest limitation presented came from the fact that this was a secondary analysis of previously collected data. Additional variables that may have impacted this study but were not measured are objective data related to the nature and causation/triggers of the Emergency Room visits and hospitalizations in the Puerto Rican children. This information gathered could have provided more insight to the cultural somatization of "ataques de nervios,"on asthma symptom perception in this population and provided more accurate data on whether this contributed to a higher utilization of emergent services compared to the Mexican population, where this is not as prevalent.

Implications for Study:

It has been demonstrated that significant discrepancies exist between parent and clinician perception of control, with subsequent data demonstrating a higher rate of acute healthcare utilization and hospitalization in Puerto Rican children. This evidence shows the necessity of the child working with both the healthcare provider and parent to identify preexisting asthma illness beliefs and working towards developing a more unified understanding of these beliefs in order to formulate a treatment regimen individualized to the child's needs. Nonadherence is more likely to occur if these asthma illness beliefs are not addressed and incorporated in to the asthma management plan.

Additionally data gathered from this study can provide evidence for an increased

need for more community based asthma programs, such as school based asthma interventions, throughout the country, as there has been indication of success in the few studies present in the literature. Through eliminating the parental factor of giving the daily dose of asthma medication, which can be influenced by the parent's own asthma illness beliefs, and transferring this to the responsibility of the school nurse, administration of the daily inhaled corticosteroids, which is crucial in the management of chronic asthma, can be ensured. This intervention can eliminate the responsibility of the parent in providing the daily asthma medications and could positively result in the decrease in asthma symptom and asthma morbidity in this population. Evidence from this study can be seen in a similar community based intervention provided by the Scottsdale Healthcare organization titled The Neighborhood Action Outreach for Health (NOAH) program, which showed a greater than 40% reduction in missed school days and a greater than 70% percent reduction in emergency room visits due to asthma-related problems, and a greater than 73% decrease in asthma-related hospital stays among Breathmobile patients since it's induction, with 77% of the population seen by this service being of Latino descent.

Recommendations

As asthma is episodic in nature, the child's ability to correctly identify asthma symptoms and the family's ability to enact an appropriate symptom management plan is critical in the optimal management of this disease and dependent on the adherence to the medication regimen prescribed (McQuaid et al., 2007). Through the further investigation of the healthcare provider in assessing previous and current asthma illness beliefs and investigating the effects of "ataques de nervios,"on asthma symptom perception in the Puerto Rican population, a more concordant perception of asthma illness management between the caregiver and clinician may occur.

Further investigation and research on community based and school based interventions is also recommended in providing an alternative means to increasing asthma medication compliance, as there has been very limited research on how to improve asthma symptom perception, despite the statistical information available for a need in improved communication and agreement between the asthmatic child's caregiver and clinician.

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The Latino Childhood Asthma Project

(05/13/10)

CHILD INTERVIEW

SESSION: *circle one* **Baseline 3-Month 6-Month 9-Month 12-Month**

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

PARENT/GUARDIAN'S INITIALS: ☐☐

CHILD'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

SECTION I. CHILD SYMPTOM INTERPRETATION

CS1. Thinking about the last 3 months: (Give an anchor - e.g. "since Christmas") please mark an "X" on the line below indicating how severe you think your asthma symptoms are.

CS2. Over the past 3 months, if you had to label your asthma, would you call it…

Mild symptoms once in a while..... 1
Mild symptoms frequently..... 2
Moderate asthma..... 3
Severe asthma 4

Children's Asthma Symptom Checklist (C-ASCL)

DIRECTIONS: Rate how often each of the following symptoms occurs during your asthma attacks. There may be other times when you have had each of these symptoms. However, please tell us how often you have each symptom ONLY when you are having your asthma attacks. [HAVE CHILD TURN TO RB2]

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA1.	Cramps	1	2	3	4	5	97	98	99
CA2.	Panting, Fast Breathing	1	2	3	4	5	97	98	99
CA3.	Numb, No Feeling	1	2	3	4	5	97	98	99
CA4.	Sticky, Mucous in Lungs	1	2	3	4	5	97	98	99
CA5.	Cranky	1	2	3	4	5	97	98	99
CA6.	Get Angry Easily	1	2	3	4	5	97	98	99
CA7.	Hard to Breathe	1	2	3	4	5	97	98	99

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA8.	Headache	1	2	3	4	5	97	98	99
CA9.	Nervous, Jittery	1	2	3	4	5	97	98	99
CA10.	Frightened	1	2	3	4	5	97	98	99
CA11.	Uncomfortable	1	2	3	4	5	97	98	99
CA12.	Short of Breath	1	2	3	4	5	97	98	99
CA13.	Heavy Feeling in Chest	1	2	3	4	5	97	98	99
CA14.	Afraid of Being Alone	1	2	3	4	5	97	98	99
CA15.	Afraid of Dying	1	2	3	4	5	97	98	99
CA16.	Unhappy with Things	1	2	3	4	5	97	98	99
CA17.	Heart Pounding	1	2	3	4	5	97	98	99
CA18.	Dizzy	1	2	3	4	5	97	98	99
CA19.	Worn Out	1	2	3	4	5	97	98	99
CA20.	Panicky	1	2	3	4	5	97	98	99
CA21.	Weak	1	2	3	4	5	97	98	99
CA22.	Pins and Needles	1	2	3	4	5	97	98	99
CA23.	Hard and Fast Breathing	1	2	3	4	5	97	98	99
CA24.	Don't Care about Things	1	2	3	4	5	97	98	99
CA25.	Feel Like You're Alone	1	2	3	4	5	97	98	99
CA26.	Wheezy	1	2	3	4	5	97	98	99
CA27.	Worried about the Attack	1	2	3	4	5	97	98	99
CA28.	Tingly in Spots	1	2	3	4	5	97	98	99
CA29.	Very Angry, Mad	1	2	3	4	5	97	98	99
CA30.	Chest Tightening	1	2	3	4	5	97	98	99
CA31.	Tired	1	2	3	4	5	97	98	99

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
CA32.	Scared	1	2	3	4	5	97	98	99
CA33.	Feel Helpless	1	2	3	4	5	97	98	99
CA34.	Chest filling up	1	2	3	4	5	97	98	99
CA35.	Lonely	1	2	3	4	5	97	98	99
CA36.	Worried	1	2	3	4	5	97	98	99
CA37.	Chest Pain	1	2	3	4	5	97	98	99
CA38.	Rundown, Weak	1	2	3	4	5	97	98	99
CA39.	Mad at the World	1	2	3	4	5	97	98	99
CA40.	Coughing	1	2	3	4	5	97	98	99
CA41.	No Energy	1	2	3	4	5	97	98	99
CA42.	Unhappy	1	2	3	4	5	97	98	99
CA43.	Worried about yourself	1	2	3	4	5	97	98	99
CA44.	Worried about Asthma	1	2	3	4	5	97	98	99
CA45.	Worried in General	1	2	3	4	5	97	98	99
CA46.	Feel Left Out	1	2	3	4	5	97	98	99
CA47.	Breathe Quickly	1	2	3	4	5	97	98	99

CACT 1 – CACT 4 (Use for children 11 or younger)

Childhood Asthma Control Test for children 4 to 11 years.

This test will provide a score that may help the doctor determine if your child's asthma treatment plan is working or if it might be time for a change.

How to take the Childhood Asthma Control Test

Step 1 Let your child respond to **the first four questions (1 to 4)**. If your child needs help reading or understanding the question, you may help, but let your child select the response. Complete the remaining **three questions (5 to 7)** on your own and without letting your child's response influence your answers. There are no right or wrong answers.

Step 2 Write the number of each answer in the score box provided.

Step 3 Add up each score box for the total.

Step 4 Take the test to the doctor to talk about your child's total score.

19 or less If your child's score is 19 or less, it may be a sign that your child's asthma is not controlled as well as it could be. Bring this test to the doctor to talk about the results.

Have your child complete these questions.

[HAVE CHILD TURN TO RB3]

1. How is your asthma today?

0	1	2	3	SCORE
 Very bad	 Bad	 Good	 Very good	

2. How much of a problem is your asthma when you run, exercise or play sports?

0	1	2	3	
 It's a big problem, I can't do what I want to do.	 It's a problem and I don't like it.	 It's a little problem but it's okay.	 It's not a problem.	

3. Do you cough because of your asthma?

0	1	2	3	
 Yes, all of the time.	 Yes, most of the time.	 Yes, some of the time.	 No, none of the time.	

4. Do you wake up during the night because of your asthma?

0	1	2	3	
 Yes, all of the time.	 Yes, most of the time.	 Yes, some of the time.	 No, none of the time.	

ACT 1 – ACT 5 (Use for children that are 12)

FOR PATIENTS:

Take the Asthma Control Test™ (ACT) for people 12 yrs and older.

Know your score. Share your results with your doctor.

Step 1 Write the number of each answer in the score box provided.

Step 2 Add the score boxes for your total.

Step 3 Take the test to the doctor to talk about your score.

1. In the past **4 weeks**, how much of the time did your **asthma** keep you from getting as much done at work, school or at home?

									SCORE
All of the time	1	Most of the time	2	Some of the time	3		4	None of the time 5	

2. During the past **4 weeks**, how often have you had shortness of breath?

More than once a day	1	Once a day	2	3 to 6 times a week	3		4	Not at all 5	

3. During the past **4 weeks**, how often did your **asthma** symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

4 or more nights a week	1	2 or 3 nights a week	2	Once a week	3		4	Not at all 5	

4. During the past **4 weeks**, how often have you used your rescue inhaler or nebulizer medication (such as albuterol)?

3 or more times per day	1	1 or 2 times per day	2	2 or 3 times per week	3		4	Not at all 5	

5. How would you rate your **asthma** control during the **past 4 weeks**?

Not controlled at all	1	Poorly controlled	2	Somewhat controlled	3		4	Completely controlled 5	

TOTAL

If your score is 19 or less, your asthma may not be controlled as well as it could be. Talk to your doctor.

FOR PHYSICIANS:

The ACT is:

- A simple, 5-question tool that is self-administered by the patient
- Clinically validated by specialist assessment and spirometry[1]
- Recognized by the National Institutes of Health

Reference: 1. Nathan RA et al. *J Allergy Clin Immunol.* 2004;113:59-65.

SECTION DM. DEMOGRAPHICS

CDM1. Now I would like to ask you about <u>your ethnic background</u>. Which of these groups would you say describes your ethnic background?

Mexican 1
Puerto Rican... 2
Cuban. 3
Dominican..... 4
Hispanic 5
Central American..... 6
South American 7
OTHER (specify)..... 8

CESSAY:
THANK YOU FOR PARTICIPATING IN THIS INTERVIEW!

IS THERE ANYTHING YOU WOULD LIKE TO TELL US ABOUT YOUR EXPERIENCE WITH ASTHMA THAT WE DID NOT COVER IN THIS INTERVIEW?

COMMENTS:

EV: INTERVIEWER EVALUATION

Answer these questions about the child after you complete the questionnaire.

CEV1. During the interview, was the child generally...

Very interested.....1
Somewhat interested.....2
Indifferent.....3
Somewhat bored.....4
Very bored.....5

CEV2. How attentive was child during the interview?

Attentive, involved, responsive.....1
Somewhat inattentive or uninvolved.....2
Easily distracted, needed urging to pay attention.....3

CEV3. In general, how quickly did child respond to questions?

Responded quickly, without hesitation.....1
Deliberated some, but responses were generally not too slow.....2
Was often slow to respond.....3
Was usually very slow to respond, needed much urging.....4

CEV4. Which questions, if any, did child have difficulty understanding?

_____

_____

_____

CEV5. How truthful did child seem?

Completely truthful.....1
Mainly truthful.....2
About half and half.....3
Mainly untruthful, evasive.....4

CEV6. At the end of the interview, did child seem to be...

Very tired.....1
Fairly tired.....2
A little tired.....3
Not tired at all.....4

CEV7. At any time during the interview, was there anyone present and able to overhear the interview?

YES.....1
NO.....2

CEV8. What else is there about the interview that will help in interpreting the data?

The Latino Childhood Asthma Project

(01/29/10)

CAREGIVER INTERVIEW

Baseline

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

CAREGIVER'S INITIALS: ☐☐

CHILD'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

Opening comments:

I am going to ask you a number of questions. We ask all of the families the same questions and therefore some might not really apply to your family, but we need to ask them anyway so that all the families get the same interview.

Some of the questions are directly related to (STUDY CHILD) and his or her activity and behaviors as related to his/her asthma. Others help us describe the general household environment.

Remember everything you tell us is held in strict confidence. The only exceptions are behaviors that pose a direct risk to you or (STUDY CHILD'S) safety. Your name is not on any of our data gathering forms. You will be identified by a 4-digit identification number.

Do you have any questions for me?

Let's begin.

SECTION I: PARENTAL ILLNESS REPRESENTATION

Thank you for agreeing to participate in this interview. We are interested in learning about what it's like for parents/caregivers to have a child with asthma and how they feel about asthma treatment. People have different ideas about managing asthma. We are interested in what you think. You will be able to help us most by just answering honestly about your point of view and opinions. We will ask you to give us your opinion about a number of asthma-related statements. The responses go from STRONGLY AGREE to STRONGLY DISAGREE.

[HAND R RESPONSE BOOKLET AND ASK THEM TO TURN TO RB1]
[READ TO R] When I read you a statement, you can just tell me the number of the choice that best gives me your opinion.

Nature of the Disease/Nature of Symptoms

In this section, we would like your perspective on what asthma is like.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI1.1	A child is free of asthma when he/she does not have symptoms	1	2	3	4	5
PI1.2	Asthma symptoms are unpredictable	1	2	3	4	5
PI1.3	Asthma symptoms come on suddenly	1	2	3	4	5
PI1.4	Asthma cannot be controlled	1	2	3	4	5
PI1.5	It's hard to figure out how bad an asthma attack is	1	2	3	4	5
PI1.6	Asthma cannot be cured **(R)**	1	2	3	4	5
PI1.7	It's more important for children with asthma to be medication-free than to be symptom-free	1	2	3	4	5
PI1.8	I have a lot of stressors related to taking care of my child's asthma right now	1	2	3	4	5
PI1.9	There is little I can do to control my child's symptoms	1	2	3	4	5

Now we would like to understand your perspective on what causes or makes asthma worse for children.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI2.1	Airway inflammation causes asthma symptoms **(R)**	1	2	3	4	5
PI2.2	Tobacco smoke can make an asthma episode worse **(R)**	1	2	3	4	5
PI2.3	Exposure to allergens can make an asthma episode worse **(R)**	1	2	3	4	5

PI2.4	Children are more likely to outgrow asthma if they only take medication when they are in real trouble with their asthma.	1	2	3	4	5
PI2.5	Asthma is caused by weak lungs.	1	2	3	4	5
PI2.6	Asthma is caused by exposure to drafts/wind.	1	2	3	4	5
PI2.7	An untreated cold or flu can cause asthma	1	2	3	4	5
PI2.8	Asthma can be inherited **(R)**	1	2	3	4	5
PI2.9	Asthma is an emotional or psychological illness	1	2	3	4	5

In this section of the interview, we would like to get your opinion on asthma medicines and their use. We will be talking about 2 kinds of asthma medications. The first kind are called "quick relief" medicines. They are for use when the child has asthma symptoms to relieve those symptoms. They have names like Proventil, Albuterol or Ventolin. The second kind are those medicines that get persistent asthma under control and keep it under control. They are taken every day whether the child has symptoms or not. Sometimes these medicines are called "maintenance medicines", or "anti-inflammatories", or "inhaled steroids". They have names like Flovent, Aerobid, Vanceril, Pulmicort, and Singulair. We realize that (STUDY CHILD'S) asthma may not be severe enough for him/her to be on these medications. We would nevertheless like your opinion of them.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI3.1	Inhaled/oral steroids work by fighting inflammation in the lungs **(R)**	1	2	3	4	5
PI3.2	Inhaled/oral steroids open up airways when they are constricted and tight	1	2	3	4	5
PI3.3	Inhaled/oral steroids work by fighting infection	1	2	3	4	5
PI3.4	Treating a child's asthma with medication now may prevent complications when he/she is older **(R)**	1	2	3	4	5
PI3.5	Using inhaled/oral steroids should be a last resort in treating asthma	1	2	3	4	5
PI3.6	Parents should try to get their children off inhaled/oral steroids as soon as possible	1	2	3	4	5
PI3.7	After a child has taken inhaled/oral steroids for a while, they won't work when they are really needed	1	2	3	4	5
PI3.8	Children with asthma are taking too many inhaled/oral steroids	1	2	3	4	5
PI3.9	Doctors are likely to over-prescribe inhaled/oral steroids.	1	2	3	4	5
PI3.10	Daily inhaled/oral steroids can make children behave differently	1	2	3	4	5
PI3.11	Taking daily medication makes a child feel different from other children	1	2	3	4	5
PI3.12	Albuterol opens airways when they are constricted and tight **(R)**	1	2	3	4	5

PI3.13	If Albuterol controls asthma symptoms then anti-inflammatory medications are not necessary	1	2	3	4	5
PI3.14	I worry about the side effects of inhaled/oral steroids	1	2	3	4	5
PI3.15	I'm worried that my child could become addicted to inhaled/oral steroids.	1	2	3	4	5
PI3.16	My child is reluctant to use an inhaler in front of other children	1	2	3	4	5
PI3.17	Most children with asthma would prefer taking an oral medication to an inhaled medication	1	2	3	4	5
PI3.18	My child thinks that taking daily medicine is a hassle	1	2	3	4	5
PI3.19	My child does not like the taste of inhaled steroids	1	2	3	4	5

These statements reflect what kind of asthma control you believe you can realistically expect for your child with asthma.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PI4.1	I believe that my child can be symptom-free most of the time **(R)**	1	2	3	4	5
PI4.2	I expect that asthma will not affect my child's school attendance **(R)**	1	2	3	4	5
PI4.3	I expect that my child will have sleep disruption due to asthma	1	2	3	4	5
PI4.4	I expect that my child can fully participate in gym and normal physical activity **(R)**	1	2	3	4	5
PI4.5	Children with asthma can expect to have symptoms several times a week	1	2	3	4	5
PI4.6	I expect that my child will have no emergency room visits or hospitalizations due to asthma **(R)**	1	2	3	4	5
PI4.7	Asthma makes children more likely to have emotional problems	1	2	3	4	5
PI4.8	I worry that something terrible will happen to my child if I'm not there	1	2	3	4	5

SECTION II: PARENT / HEALTH CARE PROVIDER INTERACTION

We are interested in how you work out the management of your child's asthma with the health care provider. We would like your opinion on what is helpful and not helpful with this interaction. Remember, all information you give us is confidential. [R CAN CONTINUE TO USE RB1]

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PCP1.1	I am sometimes reluctant to discuss my worries about asthma medicines with my child's health care provider	1	2	3	4	5
PCP1.2	My child's health care provider is clear about what medicines my child needs to control his/her asthma **(R)**	1	2	3	4	5
PCP1.3	My child has a written Action Plan for what asthma medicines to use and when to use them	1	2	3	4	5
PCP1.4	When I call the doctor's office, they understand my concerns **(R)**	1	2	3	4	5
PCP1.5	I worry about "bothering" the doctor when I have questions or worries	1	2	3	4	5
PCP1.6	I see a different health care provider every time I go to the office **(R)**	1	2	3	4	5
PCP1.7	The doctor(s) who treat my child for asthma may understand asthma in general, but they don't understand how asthma affects my child	1	2	3	4	5
PCP1.8	My child's health care provider understands how asthma affects my child's day-to-day life **(R)**	1	2	3	4	5
PCP1.9	My child's health care provider understands how my child's asthma affects our family's day-to-day life **(R)**	1	2	3	4	5
PCP1.10	I'm involved as much as I want to be in making decisions about when to give what medications **(R)**	1	2	3	4	5
PCP1.11	My health care provider's office hours are not convenient for me.	1	2	3	4	5

SECTION III: ASSESSMENT OF ASTHMA SEVERITY

I'd like to ask you some questions about your child's asthma.

AM1. At what age did your child's asthma begin?

☐☐
MONTHS OF AGE

AM2. Please tell me how much you agree with the following statement. My child's asthma is under good control.

Strongly Agree..... 1
Agree.. 2
Not Sure..... 3
Disagree 4
Strongly Disagree 5

AM3. **Thinking about the last 3 months: (Give an anchor - i.e. "since Christmas") please mark an "X" on the line below indicating how severe you think your child's asthma symptoms are.**

AM4. Over the past 3 months, if you had to label your child's asthma, would you call it…

Mild symptoms once in a while..... 1
Mild symptoms frequently..... 2
Moderate asthma..... 3
Severe asthma 4

AM5. Thinking about the past three months, is your child's asthma……

Better than usual 1
About the same as usual 2
Worse than usual..... 3

AM6. Has your child had an asthma-related visit with a health care provider in the past year?

YES.... 1
NO..... ....2 **[GO TO AM9]**

AM7. Which health care provider did you take him/her to?	AM8. When was this visit?
a.	____ MON/YR
b.	____ MON/YR
c.	____ MON/YR
d.	____ MON/YR
e.	____ MON/YR
f.	____ MON/YR

AM9. Has your child had an asthma-related visit to an Emergency Department in the past year?

YES.... 1
NO..... ....2 **[GO TO AM12]**

AM10. Which ED did you take him/her to?	AM11. When was this visit?
a.	____ MON/YR
b.	____ MON/YR
c.	____ MON/YR
d.	____ MON/YR
e.	____ MON/YR

AM12. Has your child had an asthma-related hospitalization in the past year?

YES.... 1
NO..... ....2 **[NEXT SECTION]**

AM13. Which hospital was s/he admitted to?	AM14. When was this admission?
a.	____ MON/YR
b.	____ MON/YR
c.	____ MON/YR
d.	____ MON/YR
e.	____ MON/YR

SECTION IV: ASTHMA MEDICATIONS & CONTROL

"Over the Counter"

ME1. Do you give your child over-the-counter cold or allergy medications, (for example, Robitussin, Sudafed, Claritin) to treat his/her asthma symptoms?

YES.... 1

NO..... ....2 **[GO TO ME6]**

ME2. What do you use?	ME3. Do you use (NAME) as the box or label tells you to?	ME4. How do you use (NAME)?	ME5. When (STUDY CHILD) has asthma symptoms do you use (NAME).....
a.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
b.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
c.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
d.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
e.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3
f.	YES.....1[GO TO ME5] NO.....2		Before starting or increasing prescribed asthma medications.....1 With prescribed asthma medications.....2 Instead of prescribed asthma medications.....3

MEDICATION CHECKLIST: Parent Form – NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (ex. Flovent 110)

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS REGARDING MEDICATIONS YOU HAVE GIVEN YOUR CHILD IN THE **PAST 12 MONTHS** FOR HIS/HER BREATHING PROBLEMS.

ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 =Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
QUICK RELIEF:						
a. Albuterol						
b. Atrovent						
c. Combivent (albuterol/ ipratropium)						
d. Maxair (Pirbuterol) 0.2 mg						
e. Proventil (albuterol)						
f. Ventolin (albuterol)						
g. Xopenex						
ORAL STEROIDS:						
h. Celestone (betamethasone)						
i. Medrol (methyl prednisolone)						
j. Orapred (prednisolone)						
k. Prednisone						
l. Prelone (prednisolone)						
m. Solumedrol (methyl prednisolone)						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (ex. Flovent 110)

ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 =Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12.When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
QUICK RELIEF (CONT)						
n. OTHER quick-relief: _____						
CONTROLLER						
o. Accolate (zafirlukast) 10 mg tb						
p. Accolate 20 mg tb						
q. Accolate (mg unknown)						
r. Advair 100/50 (fluticasone/salmeterol)						
s. Advair 250/50 (fluticasone/salmeterol)						
t.Advair 500/50 (fluticasone/salmeteol)						
u. Advair (mg unknown)						
v. Aerobid (flunisolide) 250 mcg/inh						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example: Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12.When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
w. Azmacort (Triamcinolone Acetonide) 100 mcg/inh						
x. Flovent 44 mcg/spray (fluticasone)						
y. Flovent 110 mcg/spray						
z. Flovent 220 mcg/spray						
aa. Flovent (mcg unknown)						
bb.Foradil 12 mcg (Formoterol)						
cc. Intal (cromolyn)						
dd. Pulmicort 0.25 (budesonide)						
ee.Pulmicort 0.5 (budesonide)						
ff. Pulmicort 200 (budesonide) Turbuhaler						
gg. Qvar 40 mcg/spray (beclomethasone HFA)						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9. How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11.If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
hh. Qvar 80 mcg/spray (beclomethasone HFA)						
ii. Qvar (mcg uk/not given)						
jj. Serevent (salmeterol)						
kk. Singulair 4 mg tablet (montelukast)						
ll. Singulair 5 mg tablet						
mm. Singulair 10 mg tablet						
nn. Singulair (mg unknown)						
oo. Symbicort (80/4.5) (budesonide/formoterol)						
pp. Symbicort (160/4.5) (budesonide/formoterol)						
qq. Theophylline						

NOTE TO INTERVIEWER: RECORD MEDICATION NAME AND STRENGTH (example (Flovent 110)						
ME6. What is the name of a medication that you have given to your child for asthma in the past 12 months?	ME7. When was the last time your child took their medication? 1= <4 hours 2= 4-8 hours 3= 8-12 hours 4= 12-24 hours 5= > 24 hours 6= 1-2 weeks 7= 2-4 weeks 8= 1 to 6 months 9= > 6 months 97= N/A 98=Refused 99=Don't know	ME8. What form Does the medication come in? 1= Inhaler 2= Nebulizer 3= Pill 4= Diskus 5= Liquid 97= N/A 98=Refused 99=Don't know	ME9.How often is the medication supposed to be taken? 1 = As needed, when symptoms act up 2 = Once daily and regardless of symptoms 3 = Twice daily and regardless of symptoms 4= Daily, before taking other asthma medications (e.g., before Flovent) 5 = Before playing sports or going to gym 6 = Before exposure to asthma triggers like animals, smoke or pollen 97= N/A 98=Refused 99=Don't know	ME10. How much medication is given per day? 1= As needed/prn 2= 1 puff/day 3= 2 puffs/day 4= 4 puffs/day 5= 6 puffs/day 6 = 1 pill/day 7= 2 pills/day 97= N/A 98=Refused 99=Don't know	ME11. If before sports or exposure to other triggers, how many times per week? 1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 7 = 7 8 = >7 97 = N/A 98=Refused 99=Don't know	ME12. When did the doctor prescribe the medication? 1= < 1 month 2= 1 to 6 months 3= 7 to 12 months 4= > 12 months 97= N/A 98=Refused 99=Don't know
rr. Tilade (nedocromil)						
ss. Vanceril 42 mcg/puff (beclomethasone CFC)						
tt. Vanceril 84 mcg/puff (beclomethasone CFC)						
uu. Vanceril (mcg unknown/not given)						
vv. Zyflo (Zileuton) 600mg tab						
ww. OTHER Controller: _____						

P-ACT: *The following questions are about your child's asthma, including symptoms, limitations, medications, asthma attacks and use of healthcare services. There are no right or wrong answers.*

During the last 4 weeks, on average, how many days per month:	**Not at all**	**1-3 days/ mo**	**4-10 days/ mo**	**11-18 days/ mo**	**19-24 days/ mo**	**Everyday**
PACT9. Did your child have any daytime asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT10. Did your child cough during the day because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT11. Did your child wheeze during the day because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT12. Did you keep your child from running, exercising, or playing sports because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT13. Did your child wake up during the night because of asthma?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT14. Did your child have an asthma attack?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
PACT15. Did your child use a rescue or quick-relief medication such as albuterol (Ventolin®, Proventil®), Xopenex® or Maxair™?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

During the last 4 weeks:	**0 times/day**	**1-2 times/day**	**3-4 times/day**	**5-6 times/day**	**≥ 7 times/day**
PACT16. On the worst day, how many times did your child use a rescue or quick-relief medication such as albuterol (Ventolin®, Proventil®), Xopenex® or Maxair™?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

During the last 12 months, how often:	**0 times/yr**	**1-2 times/yr**	**3-4 times/yr**	**5-6 times/yr**	**≥ 7 times/yr**
PACT17. Did your child take oral steroids such as prednisone (Pediapred®, Prelone®, Deltasone®, Orapred®) or Decadron® because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT18. Did your child miss school or daycare because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT19. Did your child visit an urgent care facility or a hospital emergency room (without being admitted to the hospital) because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT20. Did your child have an unscheduled visit to a doctor because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
PACT21. Did your child stay in the hospital overnight or longer because of asthma symptoms?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

SECTION VI: OTHER HELPFUL STRATEGIES FOR MANAGING ASTHMA

We've talked about the medications and treatments your doctor has prescribed. Some parents have told us about other treatments that they have used in managing their child's asthma.

HS1. Have you ever tried medications or treatments other than those prescribed by your doctor to manage your child's asthma?

YES.... 1
NO..... ....2 **[GO TO HS3]**

HS2. What have you tried?

_____

_____

_____

[ASK HS3-7 EVEN IF HS1 IS "NO". NOT ALL PARENTS MAY REALIZE THAT SOME OF THE ITEMS BELOW ARE ALTERNATIVE MEDICINES OR TREATMENTS]

[Now I'm going to ask you about specific treatments that other parents have tried to manage their child's asthma]

	HS3. Have you ever tried....to manage your child's asthma?	HS4. What did you try/use?	HS5. Was it helpful?	HS6. Are you still using it?	HS7. How often do you use...?
a. Herbal supplements (St. John's Wort, Ginkgo biloba, ma huang)?	YES.....1 NO.....2 **[GO TO HS3b]**		YES.....1 NO.....2	YES.....1 NO.....2	
b. Herbal teas (chamomile, ginger, wildroot, eucalyptus, etc.)?	YES.....1 NO.....2**[GO TO HS3c]**		YES.....1 NO.....2	YES.....1 NO.....2	
c. Special foods (garlic, onion, watercress, castor oil, cod liver oil, etc.)?	YES.....1 NO.....2**[GO TO HS3d]**		YES.....1 NO.....2	YES.....1 NO.....2	
d. Vitamins (e.g., magnesium, high dose vitamin C)?	YES.....1 NO.....2**[GO TO HS3e]**		YES.....1 NO.....2	YES.....1 NO.....2	
e. Breathing exercises (e.g., Buteyko breathing techniques)?	YES.....1 NO.....2**[GO TO HS3f]**		YES.....1 NO.....2	YES.....1 NO.....2	
f. Relaxation techniques (e.g., yoga, meditation)?	YES.....1 NO.....2**[GO TO HS3g]**		YES.....1 NO.....2	YES.....1 NO.....2	
g. Massage?	YES.....1 NO.....2**[GO TO HS3h]**		YES.....1 NO.....2	YES.....1 NO.....2	
h. Prayer for health purposes?	YES.....1 NO.....2**[GO TO HS3I]**		YES.....1 NO.....2	YES.....1 NO.....2	
i. Spinal manipulation?	YES.....1 NO.....2**[GO TO HS3j]**		YES.....1 NO.....2	YES.....1 NO.....2	
j. Rubs (camphor, Vick's vapor-rub)?	YES.....1 NO.....2**[GO TO HS3k]**		YES.....1 NO.....2	YES.....1 NO.....2	
k. Syrups (Jarabe 7)?	YES.....1 NO.....2**[GO TO HS3l]**		YES.....1 NO.....2	YES.....1 NO.....2	
l. Reflexology?	YES.....1 NO.....2**[GO TO HS3m]**		YES.....1 NO.....2	YES.....1 NO.....2	
m. Acupuncture?	YES.....1 NO.....2**[GO TO HS3n]**		YES.....1 NO.....2	YES.....1 NO.....2	
n. Other (e.g., magnets, bee stings)? (Specify)	YES.....1 NO.....2**[GO TO HS7]**		YES.....1 NO.....2	YES.....1 NO.....2	

[IF HS3 a - n are "NO", go to HS13]

HS8. Do you use the above treatments for asthma instead of prescribed medications?

YES.... 1
NO..... 2

HS9. Do you use the above treatments for asthma along with prescribed medications?

YES.... 1
NO..... 2

HS10. Have you discussed these treatments with your child's doctor?

YES.... 1
NO..... ....2 **[GO TO HS12]**

HS11. What was his/her response?

_____

_____

_____

[GO TO HS13]

HS12. Why didn't you discuss these treatments with him/her?

_____

_____

_____

HS13. Besides your health care provider, are there any other people you turn to for advice on how to manage your child's asthma (i.e., family members, clergy, healers, others with asthma)?

YES.... 1
NO..... ....2 **[NEXT SECTION]**

HS14. Who do you turn to? **[LIST EACH PERSON]**	HS15. What kinds of advice do you get from (PERSON IN HS14)?
a.	
b.	
c.	
d.	

We've talked about medicines or treatments other than those prescribed by your child's doctor that you have used to manage his/her asthma. I'd now like to ask about your use of any medicines or treatments, other than those prescribed by your doctor, to manage any illnesses or conditions you may have had.

HS16. Have you ever used any medicine or treatment other than those prescribed by your doctor or nurse to manage your illness or other health condition?

YES..... 1
NO..... 2

HS17. What did you use?	HS18. What illness or health condition did you use it for?	HS19. How long did you use (NAME OF CAM)?	HS20. Was (NAME OF CAM) helpful?	HS21. Are you still using (NAME OF CAM)?
a.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
b.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
c.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
d.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
e.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
f.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
g.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2
h.		Days.....1 Weeks.....2 Months.....3 Years.....4	YES.....1 NO.....2	YES.....1 NO.....2

SECTION VII: DEMOGRAPHICS, CULTURE & ACCULTURATION

Demographics 1

Now I'm going to ask you some questions about you and your family.

DM1. What is your relationship to the child (e.g. mother, grandmother, aunt, etc.)?

_____

DM2. How old are you? |__|__| YEARS

DM3. What was the highest grade or year in school that you completed?
(CIRCLE HIGHEST GRADE COMPLETED. GED = 12)

NO FORMAL SCHOOLING	00
ELEMENTARY SCHOOL	01 02 03 04 05 06
HIGH/VOCATIONAL SCHOOL	07 08 09 10 11 12
COLLEGE OR POST HS VOCAT SCHOOL	13 14 15 16
GRADUATE OR PROFESSIONAL SCHOOL	17 18 19 20+

DM4. What is your marital status?

Married		1
Single but have a partner		2
DM4a.	Male	|__|
	Female	|__|
Widowed		3
Divorced		4
Separated		5
Never married & don't have a partner		6

DM5. Are you currently working?

NO..... 0
YES, PART-TIME 1
YES, FULL-TIME.....2

DM6. What would you say best describes your family's standard of living? Would you say you are…..

Very well off.. 1
Living very comfortably 2
Living reasonably comfortably.....3
Just getting along 4
Nearly poor 5
Poor.....6

DM7. Now I would like to ask you about your ethnic background. Which of these groups would you say describes your ethnic background?

Mexican 1
Puerto Rican... 2
Cuban. 3
Dominican..... 4
Hispanic 5
Central American..... 6
South American 7
OTHER (specify)..... 8

DM8. What country were you born in? _____

DM9. How long have you lived in the United States?

|__|__| MONTHS 1
YEARS 2

DM10. How long has (STUDY CHILD) lived in the United States?

|__|__| MONTHS 1
YEARS 2
SINCE BIRTH 3

Below are a number of statements that evaluate changes that occur when people interact with others of different cultures or ethnic groups. For questions that refer to "COUNTRY OF ORIGIN" or "NATIVE COUNTRY," please refer to the country from which your family originally came. For questions referring to "NATIVE LANGUAGE," please refer to the language spoken where your family originally came. Please tell me the answer that best matches your response to each question. [HAVE R TURN TO RB3]

		False	Partly false	Partly true	True
DM11.	I understand English, but I'm not fluent in English.	1	2	3	4
DM12.	I am informed about current affairs in the United States	1	2	3	4
DM13.	I speak my native language with my friends and acquaintances from my country of origin.	1	2	3	4
DM14.	I have never learned to speak the language of my native country.	1	2	3	4
DM15.	I feel totally comfortable with (Anglo) American people.	1	2	3	4
DM16.	I eat traditional foods from my native culture.	1	2	3	4
DM17.	I have many (Anglo) American acquaintances.	1	2	3	4
DM18.	I feel comfortable speaking my native language.	1	2	3	4
DM19.	I am informed about current affairs in my native country.	1	2	3	4
DM20.	I know how to read and write in my native language.	1	2	3	4
DM21.	I feel at home in the United States.	1	2	3	4
DM22.	I attend social functions with people from my native country.	1	2	3	4
DM23.	I feel accepted by (Anglo) Americans.	1	2	3	4
DM24.	I speak my native language at home.	1	2	3	4

		False	Partly false	Partly true	True
DM25.	I regularly read magazines of my ethnic group.	1	2	3	4
DM26.	I know how to speak my native language.	1	2	3	4
DM27.	I know how to prepare (Anglo) American foods.	1	2	3	4
DM28.	I am familiar with the history of my native country.	1	2	3	4
DM29.	I regularly read an American newspaper.	1	2	3	4
DM30.	I like to listen to music of my ethnic group.	1	2	3	4
DM31.	I like to speak my native language.	1	2	3	4
DM32.	I feel comfortable speaking English.	1	2	3	4
DM33.	I speak English at home.	1	2	3	4
DM34.	I speak my native language with my spouse or partner.	1	2	3	4
DM35.	When I pray, I use my native language.	1	2	3	4
DM36.	I attend social functions with (Anglo) American people.	1	2	3	4
DM37.	I think in my native language.	1	2	3	4
DM38.	I stay in close contact with family members and relatives in my native country.	1	2	3	4
DM39.	I am familiar with important people in American history.	1	2	3	4
DM40.	I think in English.	1	2	3	4
DM41.	I speak English with my spouse or partner.	1	2	3	4
DM42.	I like to eat American foods.	1	2	3	4

Center for Epidemiological Depression Scale (CES-D)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **past week**: [HAVE R TURN TO RB4]

CESD1. I was bothered by things that don't usually bother me.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD2. I did not feel like eating; my appetite was poor.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD3. I felt that I could not shake off the blues even with the help of my family or friends.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD4. I felt that I was just as good as other people.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD5. I had trouble keeping my mind on what I was doing.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD6. I felt depressed.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD7. I felt everything I did was an effort.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD8. I felt hopeful about the future.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD9. I thought my life had been a failure.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD10. I felt fearful.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD11. My sleep was restless.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD12. I was happy.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD13. I talked less than usual.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD14. I felt lonely.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD15. People were unfriendly.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD16. I enjoyed life.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD17. I had crying spells.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD18. I felt sad.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD19. I felt that people disliked me.

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

CESD20. I could not get "going."

1. Rarely or none of the time (<1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of the time (3-4 days)
4. Most or all of the time (5-7 days)

Demographics 2

I'd like to ask you about the people living in your household.

[ASK DM43 FOR EACH PERSON BEFORE DM44-DM47. DO NOT INCLUDE THE RESPONDENT IN THIS GRID.]

DM43. Please give me the first name of all people living in your household. **[DO NOT INCLUDE R.]**	DM44. **[ASK OR CONFIRM:]** Is (PERSON) male or female?	DM45. How old was (PERSON) on (his/her) last birthday?	DM46. What is (PERSON'S) relationship to you?	DM47. Does (PERSON) have asthma?
a.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
b.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
c.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
d.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
e.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
f.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
g.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
h.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
i.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1
j.	MALE.....1 FEMALE.....2	____ MONTHS.....1 YEARS.....2		NO.....0 YES.....1

SECTION SN. SOCIAL NETWORKS

The next few questions are about your social life, **not including** your husband, wife, or partner.

SN1. How often do you talk on the phone or get together with family or relatives who do not live with you? Would you say…

MOST EVERY DAY	1
A FEW TIMES A WEEK	2
A FEW TIMES A MONTH	3
ONCE A MONTH	4
LESS THAN ONCE A MONTH	5

SN2. **Not including your husband, wife, or partner,** how much can you rely on relatives who do not live with you for help if you have a serious problem?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN3. **Not including your husband, wife, or partner,** how much can you open up to relatives who do not live with you if you need to talk about your worries?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN4. **Not including your husband, wife or partner,** how often do your relatives or children make too many demands on you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN5. **Not including your husband, wife or partner,** how often do your family or relatives argue with you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN6. How often do you talk on the phone or get together with friends?

MOST EVERY DAY	1
A FEW TIMES A WEEK	2
A FEW TIMES A MONTH	3
ONCE A MONTH	4
LESS THAN ONCE A MONTH	5

SN7. How much can you rely on your friends for help if you have a serious problem?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN8. How much can you open up to your friends if you need to talk about your worries?

A LOT	1
SOME	2
A LITTLE	3
NOT AT ALL	4

SN9. How often do your friends make too many demands on you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN10. How often do your friends argue with you?

OFTEN	1
SOMETIMES	2
RARELY	3
NEVER	4

SN11. When you have a problem or worry, how often do you let your husband/wife/partner know about it?
[NOTE TO INTERVIEWER: CODE N/A IF NO HUSBAND, WIFE, OR PARTNER]

ALWAYS	1
MOST OF THE TIME	2
SOMETIMES	3
RARELY	4
NEVER	5
N/A	97

SN12. When you have a problem or worry, how often do you let someone (else) know about it?

ALWAYS	1
MOST OF THE TIME	2
SOMETIMES	3
RARELY	4
NEVER	5

SECTION VIII: PARENT-CHILD ASTHMA SYMPTOM CHECKLIST (P-CASCL)

DIRECTIONS: Rate how often each of the following symptoms occurs during your child's asthma attacks. There may be other times when he/she has had each of these symptoms. However, please tell us how often he/she has had each symptom ONLY when he/she is having his/her asthma attacks. [HAVE R TURN TO RB5]

		Never	Hardly at all	Some of the time	Most of the time	Always	Refused	Don't Know	N/A
PCA1.	Cramps	1	2	3	4	5	97	98	99
PCA2.	Panting, Fast Breathing	1	2	3	4	5	97	98	99
PCA3.	Numb, No Feeling	1	2	3	4	5	97	98	99
PCA4.	Sticky, Mucous in Lungs	1	2	3	4	5	97	98	99
PCA5.	Cranky	1	2	3	4	5	97	98	99
PCA6.	Get Angry Easily	1	2	3	4	5	97	98	99
PCA7.	Hard to Breathe	1	2	3	4	5	97	98	99
PCA8.	Headache	1	2	3	4	5	97	98	99
PCA9.	Nervous, Jittery	1	2	3	4	5	97	98	99
PCA10.	Frightened	1	2	3	4	5	97	98	99
PCA11.	Uncomfortable	1	2	3	4	5	97	98	99
PCA12.	Short of Breath	1	2	3	4	5	97	98	99
PCA13.	Heavy Feeling in Chest	1	2	3	4	5	97	98	99
PCA14.	Afraid of Being Alone	1	2	3	4	5	97	98	99
PCA15.	Afraid of Dying	1	2	3	4	5	97	98	99
PCA16.	Unhappy with Things	1	2	3	4	5	97	98	99
PCA17.	Heart Pounding	1	2	3	4	5	97	98	99
PCA18.	Dizzy	1	2	3	4	5	97	98	99
PCA19.	Worn Out	1	2	3	4	5	97	98	99
PCA20.	Panicky	1	2	3	4	5	97	98	99
PCA21.	Weak	1	2	3	4	5	97	98	99

PCA22.	Pins and Needles	1	2	3	4	5	97	98	99
PCA23.	Hard and Fast Breathing	1	2	3	4	5	97	98	99
PCA24.	Doesn't Care about Things	1	2	3	4	5	97	98	99
PCA25.	Feels Like he/she is alone	1	2	3	4	5	97	98	99
PCA26.	Wheezy	1	2	3	4	5	97	98	99
PCA27.	Worried about the Attack	1	2	3	4	5	97	98	99
PCA28.	Tingly in Spots	1	2	3	4	5	97	98	99
PCA29.	Very Angry, Mad	1	2	3	4	5	97	98	99
PCA30.	Chest Tightening	1	2	3	4	5	97	98	99
PCA31.	Tired	1	2	3	4	5	97	98	99
PCA32.	Scared	1	2	3	4	5	97	98	99
PCA33.	Feel Helpless	1	2	3	4	5	97	98	99
PCA34.	Chest Filling UP	1	2	3	4	5	97	98	99
PCA35.	Lonely	1	2	3	4	5	97	98	99
PCA36.	Worried	1	2	3	4	5	97	98	99
PCA37.	Chest Pain	1	2	3	4	5	97	98	99
PCA38.	Rundown, Weak	1	2	3	4	5	97	98	99
PCA39.	Mad at the World	1	2	3	4	5	97	98	99
PCA40.	Coughing	1	2	3	4	5	97	98	99
PCA41.	No Energy	1	2	3	4	5	97	98	99
PCA42.	Unhappy	1	2	3	4	5	97	98	99
PCA43.	Worried about him/herself	1	2	3	4	5	97	98	99
PCA44.	Worried about Asthma	1	2	3	4	5	97	98	99
PCA45.	Worried in General	1	2	3	4	5	97	98	99
PCA46.	Feel Left Out	1	2	3	4	5	97	98	99
PCA47.	Breathes Quickly	1	2	3	4	5	97	98	99

SECTION IX. ASTHMA TRIGGER INVENTORY

There are many different causes for asthmatic symptoms. Situations causing symptoms can vary considerably from one person to the other. Please indicate for each of the listed causes below how often they are involved when your child experiences symptoms of asthma. Please base your answers on your *own child's experience, not* on what you think should lead to asthma for the typical patient.
The following things can trigger my child's asthma alone or in part. [HAVE R TURN TO RB6]

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS
1. Having a cold	0	1	2	3	4
2. Cigarette smoke	0	1	2	3	4
3. Running	0	1	2	3	4
4. Being angry	0	1	2	3	4
5. Pollen from trees	0	1	2	3	4
6. Feeling alone	0	1	2	3	4
7. Exhaust fumes	0	1	2	3	4
8. Bicycle riding	0	1	2	3	4
9. Stress at home	0	1	2	3	4
10. Certain intensive odors	0	1	2	3	4
11. Pollen from grass	0	1	2	3	4
12. Feeling tense	0	1	2	3	4
13. Climbing flights of stairs	0	1	2	3	4
14. Depressed mood	0	1	2	3	4
15. Smell of paint	0	1	2	3	4
16. Sport activities	0	1	2	3	4
17. Perfumes	0	1	2	3	4
18. Arguments with people	0	1	2	3	4
19. Flu	0	1	2	3	4
20. Sinus problems	0	1	2	3	4
21. Being excited	0	1	2	3	4
22. Intense worries	0	1	2	3	4
23. Feeling unhappy	0	1	2	3	4
24. Animal hair	0	1	2	3	4
25. Overexertion	0	1	2	3	4
26. Viruses	0	1	2	3	4
27. Feeling weak	0	1	2	3	4
28. Pollen from weeds	0	1	2	3	4
29. Feathers from birds	0	1	2	3	4
30. Sprays	0	1	2	3	4
31. Cats	0	1	2	3	4
32. House dust	0	1	2	3	4

PESSAY:
THANK YOU FOR PARTICIPATING IN THIS INTERVIEW!

IS THERE ANYTHING YOU WOULD LIKE TO TELL US ABOUT YOUR EXPERIENCE WITH ASTHMA THAT WE DID NOT COVER IN THIS INTERVIEW?

COMMENTS:

EV: INTERVIEWER EVALUATION

Answer these questions about the mother after you complete the questionnaire.

EV1. During the interview, was the mother generally...

Very interested.....1
Somewhat interested.....2
Indifferent.....3
Somewhat bored.....4
Very bored.....5

EV2. How attentive was the mother during the interview?

Attentive, involved, responsive.....1
Somewhat inattentive or uninvolved.....2
Easily distracted, needed urging to pay attention.....3

EV3. In general, how quickly did the mother respond to questions?

Responded quickly, without hesitation.....1
Deliberated some, but responses were generally not too slow.....2
Was often slow to respond.....3
Was usually very slow to respond, needed much urging.....4

EV4. Which questions, if any, did the mother have difficulty understanding?

_____

_____

_____

EV5. How truthful did the mother seem?

Completely truthful.....1
Mainly truthful.....2
About half and half.....3
Mainly untruthful, evasive.....4

EV6. At the end of the interview, did the mother seem to be...

Very tired.....1
Fairly tired.....2
A little tired.....3
Not tired at all.....4

EV7. At any time during the interview, was there anyone present and able to overhear the interview?

YES.....1
NO.....2

EV8. What else is there about the interview that will help in interpreting the data?

*Types of instruments

BATCH # _____

PARENT INTERVIEW – PART II
The Latino Childhood Asthma Project
(11/03/09)

STUDY ID#: _____

INTERVIEWER: _____

TODAY'S DATE: MONTH: ☐☐ DAY: ☐☐ YEAR: ☐☐

PARENT/GUARDIAN'S INITIALS: ☐☐

OFFICE USE ONLY:

PI CODED/CHECKED: _____

CODED/CHECKED: _____

RECEIVED: _____

ENTERED: _____

VERIFIED: _____

SECTION I: DEMOGRAPHICS

I have a few more questions about your child and then some general questions about you.

DM1. Tell me how much you agree with the following statement: My child's asthma is under good control.

STRONGLY AGREE 1
AGREE 2
UNSURE 3
DISAGREE 4
STRONGLY DISAGREE 5

DM2. How old is your son/daughter?

☐☐ YEARS

DM3. How old are you?

☐☐ YEARS

DM4. What was the highest grade or year in school that you completed?
(CIRCLE HIGHEST GRADE COMPLETED. GED = 12)

NO FORMAL SCHOOLING	00
ELEMENTARY SCHOOL	01 02 03 04 05 06
HIGH/VOCATIONAL SCHOOL	07 08 09 10 11 12
COLLEGE OR POST HS VOCAT SCHOOL	13 14 15 16
GRADUATE OR PROFESSIONAL SCHOOL	17 18 19 20+

DM4. What is your marital status?

a. Married ☐
b. Single but have a partner ☐
c. Widowed ☐
d. Divorced ☐
e. Separated ☐
f. Never married & don't have a partner ☐

DM5. What would you say best describes your family's standard of living? Would you say you are…..

Very well off.. 1
Living very comfortably 2
Living reasonably comfortably 3
Just getting along 4
Nearly poor 5
Poor.... 6

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week.

	<1 day	1-2 days	3-4 days	5-7 days
DM6. I was bothered by things that usually don't bother me.	0	1	2	3
DM7. I had trouble keeping my mind on what I was doing.	0	1	2	3
DM8. I felt depressed.	0	1	2	3
DM9. I felt that everything I did was an effort.	0	1	2	3
DM10. I felt hopeful about the future (R)	0	1	2	3
DM11. I felt fearful.	0	1	2	3
DM12. My sleep was restless.	0	1	2	3
DM13. I was happy. (R)	0	1	2	3
DM14. I felt lonely.	0	1	2	3
DM15. I could not "get going."	0	1	2	3

We are interested in how you work out the management of your child's asthma with the health care provider. We would like your opinion on what is helpful and not helpful with this interaction. Remember, all information you give us is confidential.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
PCP1.1	I am sometimes reluctant to discuss my worries about asthma medicines with my child's health care provider	1	2	3	4	5
PCP1.2	My child's health care provider is clear about what medicines my child needs to control his/her asthma **(R)**	1	2	3	4	5
PCP1.3	My child has a written Action Plan for what asthma medicines to use and when to use them	1	2	3	4	5
PCP1.4	When I call the doctor's office, they understand my concerns **(R)**	1	2	3	4	5
PCP1.5	I worry about "bothering" the doctor when I have questions or worries	1	2	3	4	5
PCP1.6	I see a different health care provider every time I go to the office **(R)**	1	2	3	4	5

PCP1.7	The doctor(s) who treat my child for asthma may understand asthma in general, but they don't understand how asthma affects my child	1	2	3	4	5
PCP1.8	My child's health care provider understands how asthma affects my child's day-to-day life **(R)**	1	2	3	4	5
PCP1.9	My child's health care provider understands how my child's asthma affects our family's day-to-day life **(R)**	1	2	3	4	5
PCP1.10	I'm involved as much as I want to be in making decisions about when to give what medications **(R)**	1	2	3	4	5
PCP1.11	My health care provider's office hours are not convenient for me.	1	2	3	4	5

I'd like to thank you for taking the time to talk with me today. Is there anything else that we haven't talked about that you'd like to share?

Arcoleo, Kimberly

From: Allen, Beth <Beth.Allen@nationwidechildrens.org>
Sent: Saturday, February 25, 2012 7:38 AM
To: Arcoleo, Kimberly
Subject: RE: Asthma Education Tool
Attachments: APPES Results for Pulm AAP team.pptx

Potential questions:

- What worries you the most regarding your child's asthma?
- What has been the most difficult aspect of taking care of your child's asthma?
- Short of curing your child's asthma (which can't be done - yet), what do you hope asthma treatment will accomplish?
- Do you feel like you understand what your child's medications do, and when you should use them?
- What has been most helpful for you regarding treating your child's asthma?
- Do you feel like you are completely able to manage your child's asthma if they start having symptoms? If not, why not? (what is missing?)
- What do your health care providers not understand about your child's asthma? (or What do you wish your child's healthcare providers would know about your struggle with asthma?)
- If your child takes daily medications for asthma, what has been the hardest part about giving them? What tricks have you learned that help you make sure they are given as recommended?
- Do your think other family members, friends, your child's school, understand what you are dealing with when it comes to your child's asthma?

Also - have attached a powerpoint synopsis of a study one of our medical students is submitted for presentation at the American Thoracic Society. He's working on a manuscript as well. I think it represents a different way of looking at what families understand about asthma - in a very practical way - that correlates with how their asthma is "doing." I'd love to hear what you think.

Beth

From: Arcoleo, Kimberly [karcoleo@con.ohio-state.edu]
Sent: Friday, February 24, 2012 11:43 AM
To: Gleeson, Sean; Stukus, David; Ayres, Gloria; O Connor, Christine; Bowman, Emily; Allen, Beth; Jonathan Feldman; Juliana Rodriguez (julianarguez21@gmail.com); Harris, Judith A.; Sauerhoefer, Tanya; April Hawthorne (april.hawthorne@asu.edu); Rachelle Begay (Rachelle.Begay@asu.edu); Luis E Zayas (lezayas@asu.edu); Mcgwire, Gerd
Subject: Asthma Education Tool

Hi everyone,
I thought I'd share the Asthma Education Tool we developed as well as the paper we published on the results as part of the larger AIRS study we did in Rochester. It may help guide your questions for the focus groups. I apologize for not remembering that we had done this sooner! If I could have your list by March 9th that would be great!
Warm regards,
Kim

Kimberly J. Arcoleo, PhD, MPH
Associate Professor
Director, Center for Promoting Health in
Infants, Children, Adolescents & Women